



Research Report for End of Life Choices Jersey

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Background

The organisation End of Life Choices Jersey was set up in response to the wish of many Islanders to determine how and when they end their own life, without incriminating those assisting them. Alongside sharing information and opinions on end-of-life choices, they are campaigning for a change in Jersey law to enable doctors the legal right to assist in the death of mentally competent patients with incurable health problems that result in their perceived quality of life falling permanently below the level they are able to accept, without infringing criminal law.

End of Life Choices Jersey commissioned an independent survey from 4insight to gather Islanders views on end-of-life choices here in Jersey. Questions were designed around a recently completed UK survey designed and conducted by The National Centre for Social Research, sponsored by 'My Death, My Decision', allowing Islanders views to be directly compared to those of UK residents.

Survey participants were shown three similar scenarios which included many aspects that were perceived important safeguards in those countries that have assisted dying legislation. It also focused on the dying person's own assessment of their quality of life that they were prepared to accept. A fourth scenario was then shown and tested that concerned those suffering from Alzheimer dementia.

Specific objectives of the research included:

- exploring islanders' views on end-of-life choices and assisted dying
- comparing results to the recent 'My Death, My Decision' survey in the UK

Executive Summary

The independent survey completed by 1,420 islanders, testing the 4 different scenarios demonstrated that 63% of respondents believed that assisted dying was “always acceptable” when the condition would eventually cause death, rising to 70% when the condition would cause death in the next 6 months.

Across all scenarios shown, between 86.5% and 92% of respondents believed that assisted dying would be acceptable to some extent, even if just rarely.

When the condition would not cause death, a greater proportion of respondents believed that it was only “sometimes acceptable” (41.7%).

The proportion of respondents answering “never acceptable” ranged from 8% to 13.5%.

A greater proportion of respondents with no religion believed that assisted dying was always acceptable.

There were no significant differences between the views of males and females, or between respondents from the different parishes of the Island.

As age increased, the proportion of respondents believing that assisted dying is “never acceptable” increased.

The % respondents who stated “always acceptable” for the various scenarios were overall higher in Jersey than in the UK.

Scope, Sample and Methodology

The **scope** of this research was with those living in Jersey aged 18 and above.

An **online structured survey** was programmed and hosted by 4insight around the same scenarios as the recently completed UK survey designed and conducted by The National Centre for Social Research, with the addition of Jersey tailored demographics.

The survey link was available for all to complete, with invitations to take part delivered via email to 4insight's representative panel of over 2,800, plus End of Life Choices Jersey press releases/interviews addressing social and traditional local media. Respondents completed the survey between the 7th of June 2019 and the 9th of July 2019. The online survey was optimised for easy completion on Smartphone, tablet, laptop and PC. Some street activity and interviews were also conducted with iPads to survey those less digitally confident.

The survey included some demographic information such as age, parish lived in, gender and faith. The survey received responses from a range of individuals from these differing demographics and details of these can be found in the appendix.

In total 1,595 responses were received from the survey. Following data cleaning (removing short partial results, any repeats, flat-lining answers and exclusions), 1,420 total responses were captured and analysed with cross tabulations being conducted to explore if there were any differences by demographic segment.

The Survey

In the survey respondents were asked to give their views on assisted dying in various scenarios.

Survey respondents were firstly shown the following vignette, before being asked the extent to which they believed that it was acceptable for a doctor to assist that person to die in various scenarios.

*John/Hannah has been diagnosed with an incurable medical condition that **will eventually cause his/her death.***

He/She is currently mentally competent and has asked several times to be medically assisted to die because his/her quality of life has fallen permanently below a level he/she is willing to accept.

His/Her case has been approved by two doctors and checked by independent professionals to ensure that this is his/her free and informed choice.

In scenario one, respondents were asked how acceptable they thought it would be for a doctor to assist someone to die when they were in the scenario above, where the condition would eventually cause death. 63% of respondents believed that in the scenario above, a doctor assisting someone to die would be “always acceptable”, with 25.6% believing it would be “sometimes acceptable”. A much smaller 3.6% thought that it would be “rarely acceptable”, with 8% of respondents believing that it was “never acceptable”.

In the second scenario posed to respondents, the phrase “*will eventually cause death*” in the question was replaced with “*will cause death in the next 6 months*”, with all other wording remaining identical. In this scenario, the proportion of respondents who believed that it was **“always acceptable” increased to 70%**, with 19% believing it would be “sometimes acceptable”. Whilst the overall level of support is similarly high, a notable shift is seen moving from “sometimes” to “always”. The proportion of respondents who thought that it was “rarely acceptable” or “never acceptable” remained very similar at 3% and 8% respectively.

In the third scenario, the requirement of the patient having a terminal illness was removed all together, with the phrase “*will eventually cause death*” being replaced by the phrase “***will not directly cause death***”. In this scenario, “sometimes acceptable” became the most common answer at 41.7%, with a lower proportion of respondents, 34%, believing that it

was “always acceptable”. In this scenario, where the condition would not directly cause death, the proportion of respondents believing that it was “rarely acceptable” increased to 11%. The proportion believing that it was “never acceptable” also increased to 13.5%.

In the next vignette, respondents were presented with a scenario where an individual was suffering from dementia but had not yet lost mental capacity.

Steve/Annabel has been diagnosed with Alzheimer dementia, an incurable medical condition that will eventually cause his/her death but may take 7 or more years of decline to do so. Symptoms of late stage dementia include, among others, loss of mental capacity.

He/She is currently mentally competent, and has asked several times to be medically assisted to die before he/she loses mental capacity and his/her quality of life falls permanently below a level he/she is willing to accept.

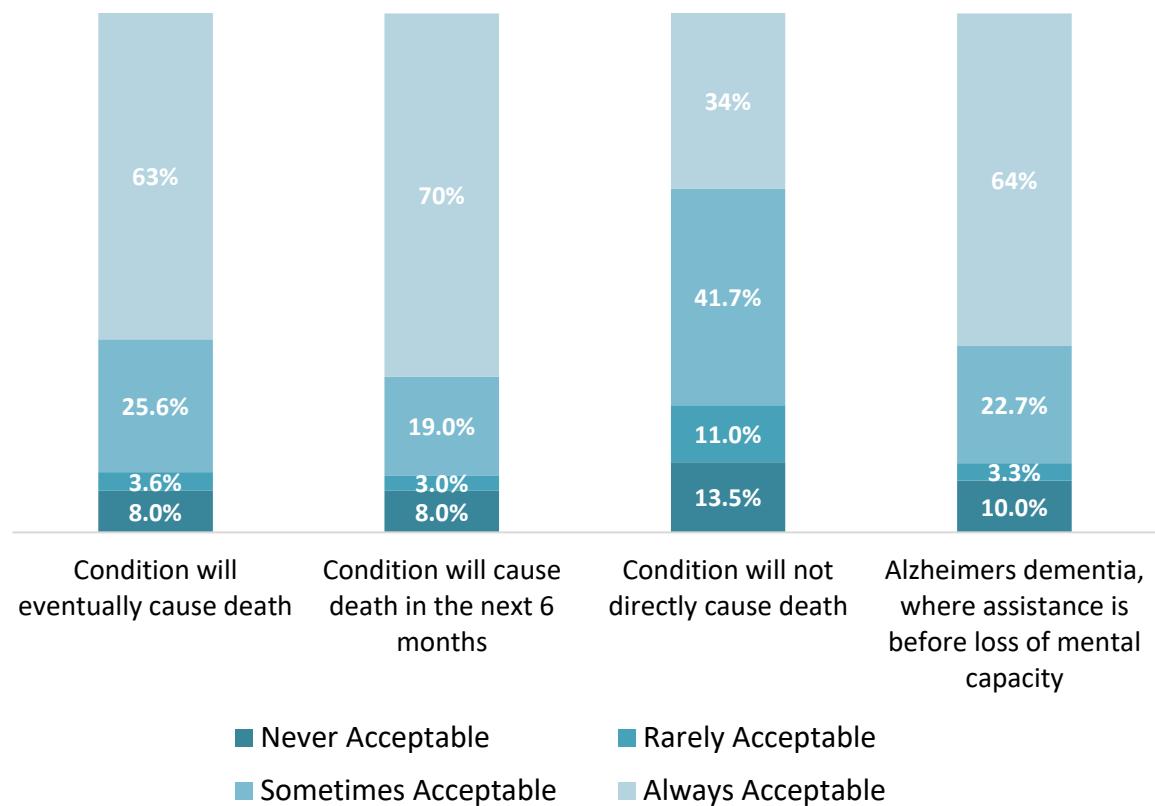
His/Her case has been approved by two doctors and checked by independent professionals to ensure that this is his/her free and informed choice. Once Steve/Annabel has lost mental capacity he/she would not be able to have a medically assisted death.

After having read the vignette, respondents were again asked:

In your opinion, to what extent is it acceptable for a doctor to assist Steve/Annabel to die at a time of his/her choosing before he/she has lost mental capacity and his/her quality of life falls permanently below a level he/she is willing to accept?

In this scenario, 64% of respondents believed that a medically assisted death was “always acceptable”, whilst a smaller 23% thought it was “sometimes acceptable”. The proportion of respondents believing that it was “rarely acceptable” or “never acceptable” was similarly low again at 3% and 10% respectively.

How acceptable is it for a doctor to assist someone to die when they have an incurable medical condition that reduces their quality of life below the level they can accept?



Across all four of the scenarios, only 8% to 14% of respondents believed that assisted dying was “never acceptable”. Thus, across these scenarios, between 86% and 92% of respondents believed that it would be acceptable to some extent, even if just rarely.

Wills and Lasting Power of Attorney

Respondents were also asked whether they had set up a Will, a Living Will (Advanced Decision to Refuse Treatment), or a Lasting Power of Attorney. It was found that 54% of respondents had set up a Will, 6% had set up a Living Will and 5% had set up a Lasting Power of Attorney. The remaining 44% of respondents had set up “none of the above”.

Answers by age, gender and faith

Faith

When asked “*What is your faith?*”, 43% of respondents selected ‘no religion’. The remaining 57% of respondents represented a good mix of different religions, including Christian, Roman Catholic, Church of England/Anglican, Baptist, Methodist, Hindu, Jewish, Muslim, Buddhist and other non-Christian. 4% of respondents preferred not to say.

Across all scenarios, the proportion of respondents believing that a doctor assisted death was ‘always acceptable’ was higher in the ‘no religion’ group. Similarly, the proportion of respondents believing that a doctor assisted death was ‘never acceptable’ across the four scenarios was lower in this group.

A significantly greater proportion of Baptist respondents (7 respondents) believed that assisted dying was “never acceptable”, ranging from 71% to 100% across the four scenarios.

Age

When results were analysed and age differences observed, a trend was seen across all four scenarios in the proportion of respondents believing that assisted dying is “never acceptable”. As the age of the respondents increased, the proportion of them believing that assisted dying was “never acceptable” also increased. For instance, in the first scenario where respondents are told that the condition will eventually cause death, 4% of 18 to 29 year olds selected “never acceptable”, rising to 7% of 40 to 49 year olds, 10% of 60-69 years olds and 14% of 70 to 79 year olds. This same pattern was seen in all four scenarios.

Furthermore, the proportion of respondents believing that assisted dying is “always acceptable” in each of the four scenarios was lower in the 60 to 69 years old and 70 to 79 years old groups, although it was still the majority view that it was acceptable. As age increased, the proportion of respondents who had set up a Will, a Living Will or a Lasting Power of Attorney also increased, and the proportion of respondents who hadn’t set up any of the above decreased.

Gender

There were no statistically significant differences in the answers of male and female respondents across all four scenarios.

However, the proportion of respondents setting up a Will, a Living Will or a Lasting Power of Attorney was higher in males; 64% of male respondents set up a Will, compared to 50% of female respondents, 7% of male respondents set up a Living Will, compared to 5% of female respondents, and finally, 6% of male respondents set up a will, compared to 4% of female respondents.

Parish of Residence

There were no statistically significant differences in the answers of respondents living in different parts of the island across all four scenarios, or in the proportion of respondents who had set up a Will, a Living Will or Power of Attorney.

Comparisons to the UK Survey

Alongside aiming to gather Islanders views on assisted dying, the survey was also developed in such a way that it would allow responses to be compared to those of UK residents who completed the similar survey designed and conducted by The National Centre for Social Research, sponsored by 'My Death, My Decision'. This survey had a representative sample of 2,708 UK residents aged 18 and above. (Note that the Jersey population sample is a much higher population % sample at 1.3%).

Scenario 1

In scenario one, respondents were asked how acceptable they thought it would be for a doctor to assist someone to die when the condition would eventually cause death.

The proportion of respondents who believed that it was either "sometimes" or "always acceptable" was very similar in both the Jersey (89%) and UK (87%) surveys. However, the distribution of those believing it was "always acceptable" and those believing it was "sometimes acceptable" differed between the two surveys. 4insight's survey results found that a greater proportion of Jersey respondents believed that it would be "always acceptable"; 63% compared to 47% in the UK survey. Additionally, the proportion of respondents selecting "sometimes acceptable" in the UK survey was higher (40%) than the proportion of Jersey respondents (25.6%).

The proportion of individuals believing that it was either "rarely acceptable" or "never acceptable" were similar in both surveys; 3.6% of Jersey respondents believing that it was "rarely acceptable", compared to 6% of respondents in the UK survey, and 8% of Jersey respondents believing that it was "never acceptable", compared to 7% of respondents in the UK survey.

Scenario 2

In the second scenario, the phrase "*will eventually cause death*" was replaced with "*will cause death in the next 6 months*".

In the UK survey, the proportion of respondents believing that assisted dying in this scenario was either "always" or "sometimes acceptable" decreased from 87% in scenario one, to 78% in scenario two. In our survey, however, the proportion of Jersey respondents believing that assisted dying in this scenario was either "always" or "sometimes acceptable" did not decrease from the 89% of respondents in scenario one. Again, however, the proportion of Jersey respondents who believed that it was "always acceptable" was higher (70%) than the proportion of respondents in the UK survey (45%). Moreover, fewer Jersey respondents believed that it was "sometimes acceptable" (19%), compared to respondents in the UK survey (33%).

Fewer Jersey respondents in this survey believed that it was either “rarely acceptable” or “never acceptable”, with only 3% of Jersey respondents believing that it was “rarely acceptable”, compared to 10% of respondents in the UK survey, and 8% of Jersey respondents believing that it was “never acceptable”, compared to 12% of respondents in the UK survey.

Scenario 3

In the third scenario, the requirement of the patient having a terminal illness was removed altogether, with the phrase “*will eventually cause death*” being replaced by the phrase “*will not directly cause death*”.

Responses for this question were very similar in both surveys.

In this Jersey survey, 41.7% of respondents answered, “sometimes acceptable”, 34% of respondents selected “always acceptable”, 11% thought that it was “rarely acceptable”, and 13.5% believed that it was “never acceptable”.

Similarly, in the UK survey, 44% of respondents answered “sometimes acceptable”, 32% of respondents selected “always acceptable”, 12% thought that it was “rarely acceptable”, and 12% believed that it was “never acceptable”.

Scenario 4

In the final scenario, respondents were presented with a scenario where an individual was suffering from dementia but had not yet lost mental capacity.

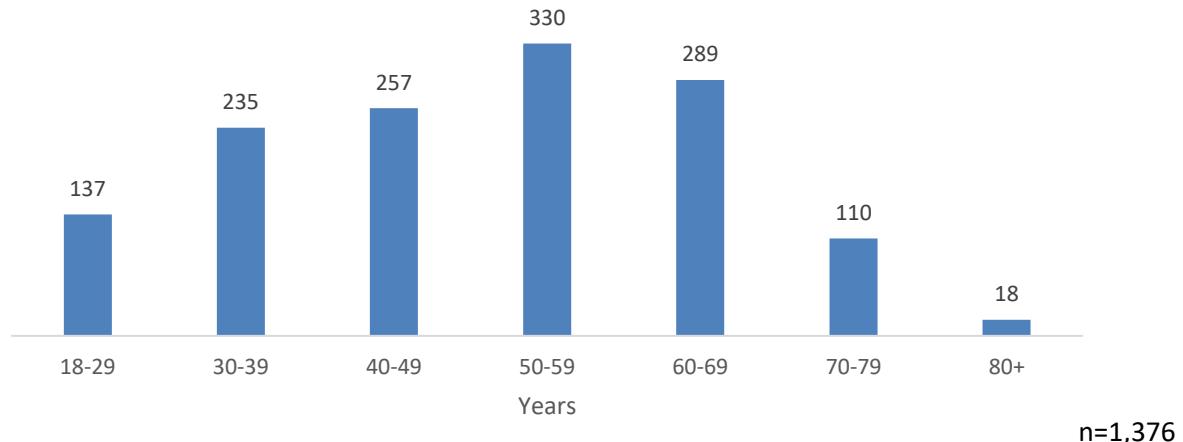
Responses to this question differed from those seen in the UK survey. Whilst 77% of respondents in the UK survey answered “always acceptable” (36%) or “sometimes acceptable” (41%), a greater 87% of respondents in the Jersey survey answered “always acceptable” (64%) or “sometimes acceptable” (23%). This difference can be seen most notably in the great difference between respondents answering “always acceptable” in each survey, with significantly more Jersey respondents believing that assisted dying is “always acceptable”.

Fewer respondents in the Jersey survey thought that assisted dying was “rarely acceptable” or “never acceptable”, compared to responses from the UK survey; 3% of Jersey respondents believed that it was “rarely acceptable”, compared to 11% of respondents in the UK survey, and 10% of Jersey respondents believed that it was “never acceptable”, compared to 12% of respondents in the UK survey.

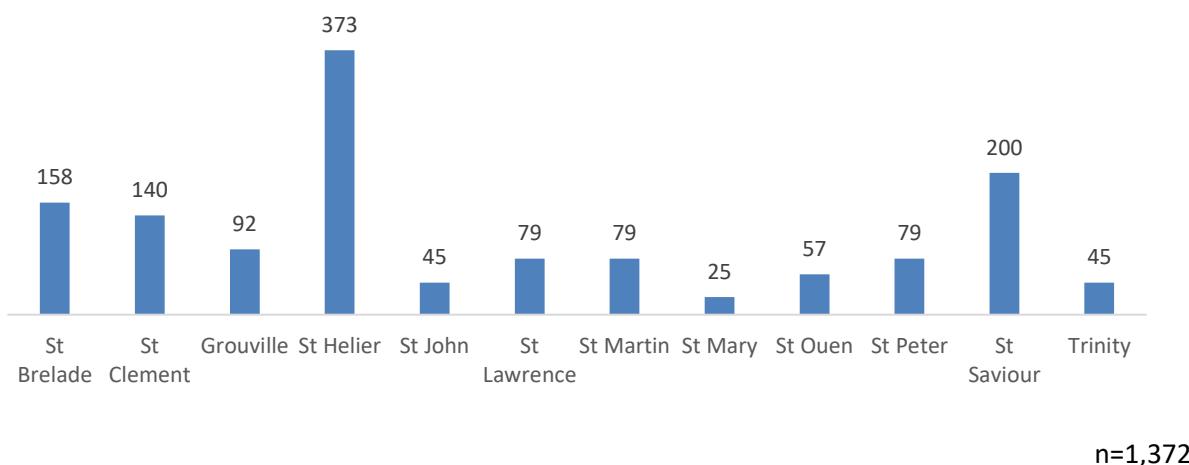
Appendix

A good demographic spread of Jersey respondents

Age, number of respondents



Parish of Residence, number of respondents



Gender, %

