Isle of Man Government
Reiltys Ellan Vannin

Department of Health and Social Care

Rheynn Slaynt as Kiarail y Theay

Summary of Consultation Responses on:

Capacity Policy Principles

January 2021

Delivering Longer Healthier Lives

HEALTH AND SOCIAL CARE IN THE ISLE OF MAN 2016 - 2021 5 YEARS. 5 GOALS.

C committed A appreciative R respectful E excellent

We asked

The purpose of the consultation was to seek the views of the public and the relevant professional persons and bodies regarding the Department of Health and Social Care's ("the Department") development of policies that will shape the Island's Capacity Laws.

You said

A total of **154** responses were received to the Consultation, 131 from individuals and 23 from organisations.

Overall, there was strong support of the need for a modern and clear legal framework for people who may have lost the capacity to make decisions for themselves and consensus as to what the overarching principles should look like.

We did

The results have been analysed and the written submissions have being assessed with attributing themes applied to enable the Department to properly consider each response in full for the purpose of informing the content of the Capacity Bill.

After considering the outcomes of this consultation, the Department will progress a public consultation on a draft Capacity Bill during Spring 2021.

This consultation response report is published online at: https://consult.gov.im/we_asked_you_said/

Contents

1. Background

Capacity issues potentially affect everyone. A person's capacity to make decisions may be impaired for a variety of reasons, such as having a significant learning disability or learning difficulties, mental health problems, suffering a stroke or head injury, or the onset of dementia. It is essential that services for people who may have lost capacity to make decisions for themselves are underpinned by a modern and legal framework.

A framework which is clear and safeguards their individual rights, dignity and wellbeing. The core policies proposed by the Department of Health and Social Care within this consultation stage proposes the basis for the Island's new Capacity laws draw inspiration from the Mental Capacity Act 2005, in England and Wales. The DHSC considered the amendments that have been made to that Act by the Mental Capacity (Amendment) Act 2019 and legislation in other neighbouring jurisdictions.

It has been a long standing intention of the DHSC to introduce legislation to improve and modernise the safeguards for those who may lack capacity and those involved in their lives.

The modernisation and establishing the common law duty on practitioners as well as providing legal governance status and protection for the health and well-being of individuals is an integral part of the modern health and social care system.

This consultation invited the views of everyone but anticipated strong interest from health and care practitioners and private, voluntary and community sector organisations working with those who lack capacity and their families.

2. Report Format

This consultation report provides a full record of comments and feedback provided during the policy principles consultation which was promoted online between August 2020 and early October 2020.

During the formulation of policy stages there is a balance between inviting open comments v's closed questions to identify key issues and options for further development.

The report format presents the statistical responses for each individual question followed by the DHSC response. A summary of extensive comments provided have been reproduced and a response provided by the DHSC that will help shape the next stage of the capacity legislation formulation.

3. Summary of Responses

A summary of key responses is presented in Appendix 1.

Additional specific comments (invited by open questions) are also summarised in Appendix 3 - 112 for a complete record of the consultation process.

4. Conclusions

As a part of this project the Department has sought the views of the public on the policies that will shape the Bill and is now in the position to tell people the impact of their contribution by publishing feedback and a summary of responses on the Government's Consultations webpage. The summary of responses to the consultation, as outlined and presented in the Appendix, explains how the responses are to be used to make decisions and inform policies for the purposes of the Capacity Bill.

The overriding business objective is to bring forward a Capacity Bill. It is essential that the provision of services for people who may have lost the capacity to make decisions for themselves are underpinned with a modern and clear legal framework which safeguards individual rights, dignity and wellbeing.

A total of 154 responses were received. Overall, there was strong support of the need for a modern and clear legal framework for people who may have lost the capacity to make decisions for themselves, and a general consensus as to what the overarching capacity principles should, in the new Capacity Act, be.

The Department would like to express their appreciation to both the organisations and individual members of the public who took the time to compete this consultation. We have attempted to respond to comments within the 'We will' mechanism in the report to provide you with the assurances on what action is likely to be progressed in light of the consultation responses provided.

We have considered each response submitted however for the purposes of this Consultation Response, given this is at policy formulation stages we have attempted to report on as much detail as possible.

As outlined in the Appendix, With regards to the responses that the Department has received some require further consideration and a decision, for the purposes of providing revised drafting instructions to Chambers and finalising the provisions of the draft Bill.

If you have responded to the consultation and feel that your comment or concern has not been addressed, please contact us in the following way:

Email: dhscconsultation@gov.im Telephone: 642608

Address: Crookall House, Demesne Road, Douglas, Isle of Man, IM1 3QA

5. Next Steps

The Capacity Bill is under construction based on the principles outlined in this report and subsequent to the formulation of these policy areas, the DHSC intend to conduct during a public consultation on the Capacity Bill itself during Spring 2021.

Capacity Policy Consultation Response

1. What is your Name?

There were 146 responses to this part of the question.

2. What is your email?

There were 137 responses to this part of the question

3. May we publish your response?

Table 3.1: There were 154 responses to this part of the question.

Option	Total	Percent
Yes, you can publish my response in full	**45**	29.2%
Yes, you may publish my response anonymously	**84**	54.6%
No, please do not publish my response	**25**	16.2%
Not Answered	**0**	0.0%

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4. If you are completing the survey as an Individual, please select the category that describes you best:

Table 4.1 There were 136 responses to this part of the question.

Option	Total	Percent
Carer	**12**	**7.8%**
Family/friend	**16**	**10.4%**
Isle of Man Resident	**51**	**33.1%**
Non-Isle of Man Resident	**0**	**0%**
Politician (national)	**1**	**0.7%**
Politician (local)	**1**	**0.7%**
Care Facility Owner	**0**	**0%**
Legal Professional	**6**	**4.0%**
Care Provider (private)	**4**	**2.6%**
Care Provider (public sector)	**7**	**4.5%**
Health or Welfare Professional	**24**	**15.6%**
Medical Professional/GP	**5**	**3.0%**
Other (please specify below)	**9**	**6.0%**
Not Answered	**18**	**11.6%**

5. If you are completing the survey on behalf of an Organisation or group, please provide the name of the organisation (or group):

Table 5.1 There were 23 responses to this part of the question, examples provided below

(with permission to publish their responses include):

Sapphire Care Limited	British Red Cross	Graih
Carters Advocates	Compassion in Dying	Attorney General's Chambers, Isle of Man
Crossroads	Pringle Law	Adult Social Care/Older Persons
Legal Aid Committee	Kerruish Law	Services(DHSC)
	Health Service Consultative Committee (HSCC)	

Which category best describes your organisation:

Table 5.1 There were 33 responses to this part of the question.

Option	Total	Percent
Political (national)	**0**	0.0%
Political (local)	**1**	0.7%
Care Facility	**1**	0.7%
Legal Profession	**6**	3.9%
Care Provision (private)	**1**	0.7%
Care Provision (public)	**3**	2.0%
Charity	**9**	5.8%
Health or Welfare Sector	**3**	2.0%
Carer	**4**	2.6%
Other (please specify below)	**5**	3.3%
Not Answered	**121**	78.6%

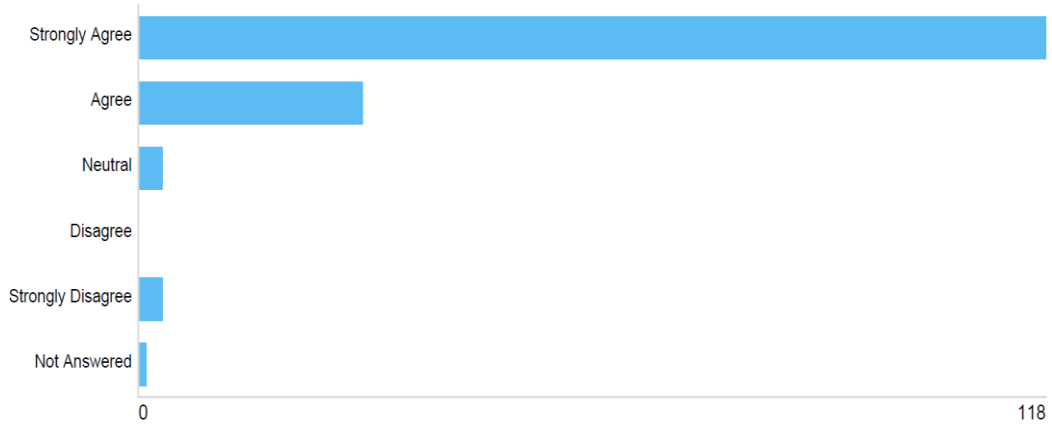
Proposals

6. Do you agree that specific legislation to assist with Capacity issues is required on the Isle of Man?

Table 6.1 There were 153 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**118**	76.6%
Agree	**29**	18.8%
Neutral	**3**	2.0%
Disagree	**0**	0.0%
Strongly Disagree	**3**	2.0%
Not Answered	**1**	0.7%

Figure 6.1 Support for specific legislation to assist with capacity issues is required on the Isle of Man



DHSC Response:

You told us:	We Will Do:
95.45% agreed that specific Legislation is required	Develop a Draft Capacity Bill upon which we will publically consult.

7. The name of the Isle of Man Act is proposed as 'The Capacity Act'. In England it is called the Mental Capacity Act and in Scotland the Adult with Incapacity Act. Please choose one of the following, or recommend an alternative name.

Table 7.1 There were 153 responses to this part of the question.

Option	Total	Percent
Capacity Act	**83**	53.9%
Assisted Capacity Act	**5**	3.3%
Supported Capacity Act	**14**	9.1%
Adult Capacity Act	**12**	7.8%
Mental Capacity Act	**34**	22.1%
Incapacity Act	**0**	0.0%
Other	**5**	3.3%
Not Answered	**1**	0.7%

Figure 7.1 Name of Legislation

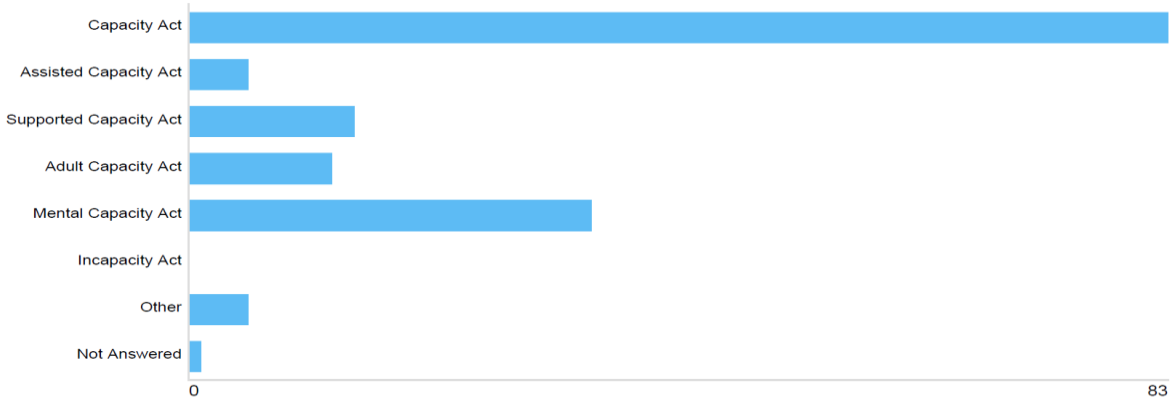


Table 7.2 Other suggestion: There were 10 responses to this part of the question.

Adults with Incapacity Act Isle of Man Mental Health Act Functional competency Act Capacity and Lucidity Act The name of the Bill should make it very clear what the legislation relates to	Mental Capacity and Assisted Decision Making Act Adult Supported Capacity Act The use of the word "mental" in the name should be avoided as otherwise it will be perceived to be the responsibility of Mental health Services.

DHSC Response:

You told us:	We Will Do:
Majority would like Legislation to be called the Capacity Act	The Department will call the Act The Capacity Act

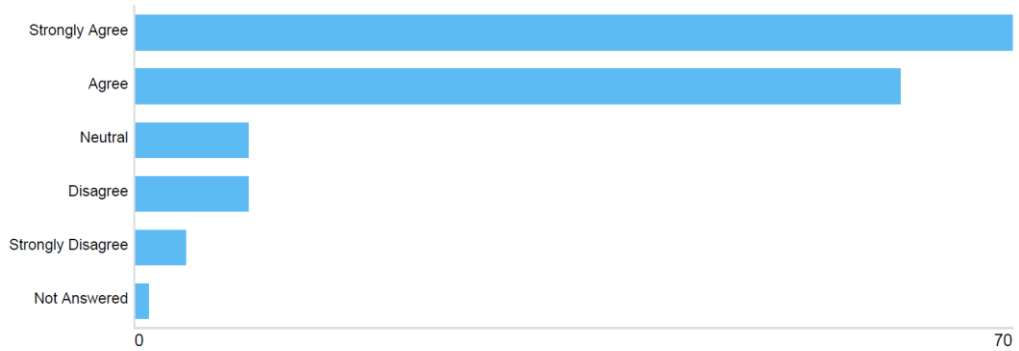
Capacity Test

8. Do you agree with proposed test to decide whether a person is unable to make a decision for themselves?

Table 8.1 There were 153 responses to this part of the question.

Option	Total	Percent
Strongly Agree	70	**45.5%**
Agree	61	**39.6%**
Neutral	9	**5.8%**
Disagree	9	**5.8%**
Strongly Disagree	4	**2.6%**
Not Answered	1	**0.7%**

Figure 8.1 Support for the proposed test to decide whether a person is unable to make a decision for themselves?



DHSC Response:

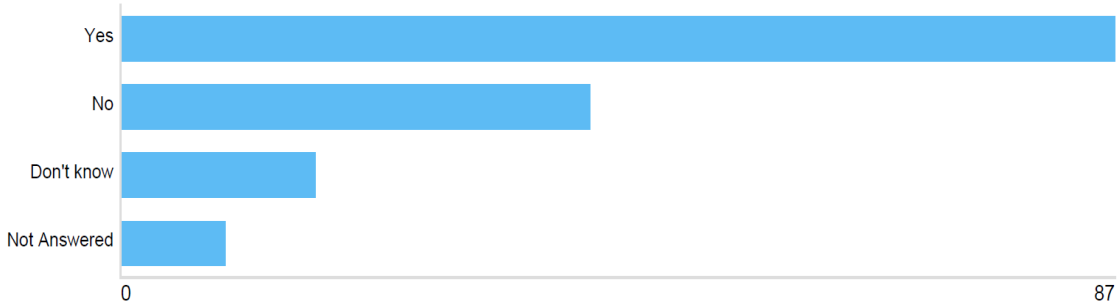
You told us:	We Will Do:
Majority 86.06% agree with the proposed test principles	The proposed Capacity test will be incorporated into the Capacity

9. Do you think anything else should be taken into consideration to decide whether a person is unable to make a decision for themselves?

Table 9.1 There were 145 responses to this part of the question.

Option	Total	Percent
Yes	**87**	56.5%
No	**41**	26.6%
Don't know	**17**	11.0%
Not Answered	**9**	5.8%

Figure 9.1: Support for other matters to be taken into consideration to decide whether a person is unable to make a decision for themselves?



DHSC Response:

You told us:	We Will Do:
Majority 56.49% felt more factors should be taken into consideration	Fully consider all the additional factors that have been raised when developing the draft Capacity Bill and the Code of Practice. There were 92 specific responses to this. For reference these are summarised in Appendix 3.

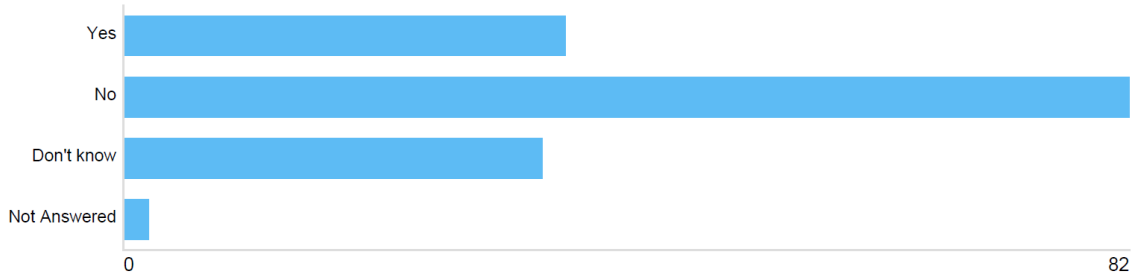
Best Interests

10. Do you think there should be any additions to this list of rules?

Table 10. 1There were 152 responses to this part of the question.

Option	Total	Percent
Yes	**36**	23.4%
No	**82**	53.3%
Don't know	**34**	22.1%
Not Answered	**2**	1.3%

Figure 10.1 Support for additional rules for Best Interest Test



DHSC Response:

You told us:	We Will Do:
• Whilst 53.25% agreed that the best interest rules proposed were adequate, 23.38% advised they thought additions were needed.	Fully consider the additional factors raised when developing the draft Capacity Bill, the Code of Practice. In particular the processes and procedures that will be put in place to monitor actions to reassure the public that the rules agreed to in principle are applied with concerns identified safeguarded. There were 44 specific responses to this. For reference these are summarised in Appendix 4

11. Do you agree with our proposal that additional weight should be given to the wishes of the person lacking capacity?

Table 11. 1 There were 153 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**87**	56.5%
Agree	**49**	31.8%
Neutral	**10**	6.5%
Disagree	**5**	3.3%
Strongly Disagree	**2**	1.3%
Not Answered	**1**	0.7%

Figure 11.1 Support for additional weight being given to the wishes of the person lacking capacity

DSHC Response:

You told us:	We Will Do:
• 88.31% agreed that additional weight should be given to wishes of the person lacking capacity	Make it clear on the face of the Act that additional weight should be given to the wishes of the person lacking capacity. There were 35 specific responses to this. For reference these are summarised in Appendix 5

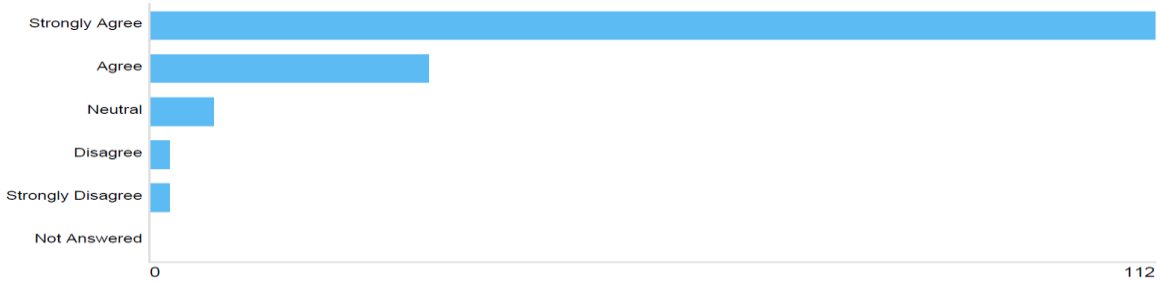
Powers of Attorney

12. Do you agree with this statement: 'A person with capacity should be able to appoint someone else to make health and welfare decisions for a time when they can no longer make these decisions themselves'

Table 12.1 There were 154 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**112**	72.7%
Agree	**31**	20.1%
Neutral	**7**	4.6%
Disagree	**2**	1.3%
Strongly Disagree	**2**	1.3%
Not Answered	**0**	0.0%

Figure 12.1 Agreement of appointment of someone else to make health and welfare decisions



DHSC Response:

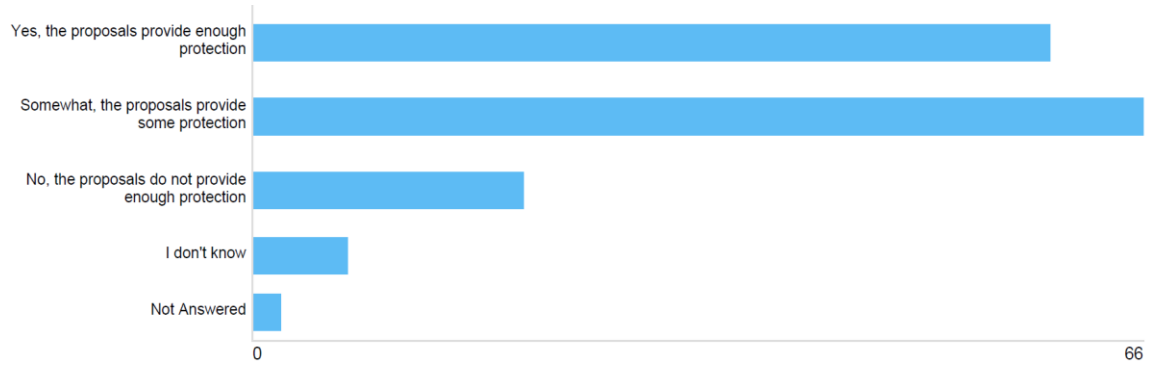
You told us:	We Will Do:
92.86% agreed that a person should be able to appoint a representative	To make provision in the Bill allowing for persons to make powers of attorney concerning health and welfare decisions.

13. Do you think the safeguards that we are proposing go far enough to protect donors from potential problems with a Lasting Power of Attorney?

Table 13.1 There were 152 responses to this part of the question.

Option	Total	Percent
Yes, the proposals provide enough protection	**59**	38.3%
Somewhat, the proposals provide some protection	**66**	42.9%
No, the proposals do not provide enough protection	**20**	13.0%
I don't know	**7**	4.6%
Not Answered	**2**	1.3%

Figure 13.1 Are proposals going far enough to protect donors from potential problems with a Lasting Power of Attorney?



DHSC Response:

You told us:	We Will Do:
• 55.85% indicate that more safeguards are required.	Fully consider all the safeguarding concerns raised and as to how they can be met when developing the draft Capacity Bill and the Code of Practice. There were 61 specific responses to this. For reference these are summarised in Appendix 6

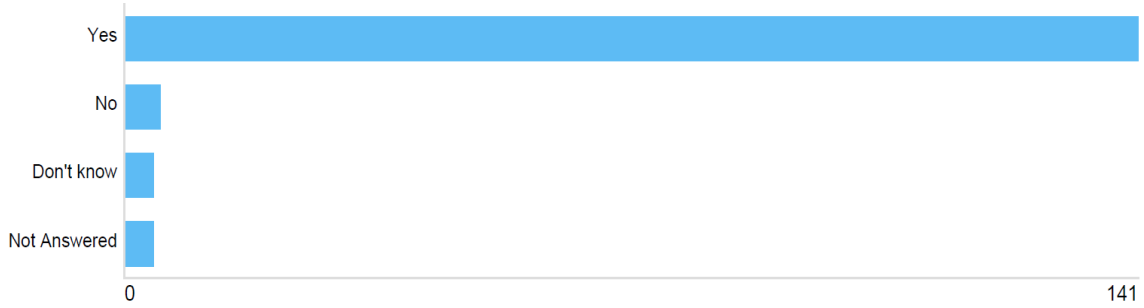
Donees

14. Do you think there should be minimum requirements applied for someone to be able to act as a donee?

Table 14.1 There were 150 responses to this part of the question.

Option	Total	Percent
Yes	**141**	91.6%
No	**5**	3.3%
Don't know	**4**	2.6%
Not Answered	**4**	2.6%

Figure 14.1 Support for minimum requirements applied for someone to be able to act as a donee



DHSC Response:

You told us:	We Will Do:
91.56% agreed that there should be minimum requirements for someone to acts as donee.	Minimum requirements as to who can act as a donee will be provided for in the Capacity Bill or in secondary legislation which will be subject to public consultation

15. Minimum Requirements for donee: If so, which of the proposed requirements do you agree with?

Table 15.1 There were 149 responses to this part of the question.

Option	Total	Percent
Aged 18 or over	**141**	91.6%
Must not be bankrupt	**127**	82.5%
Must not be the subject of a debt relief order	**119**	77.3%
Will undertake the duty to act with the general knowledge, skill and experience that may be reasonably expected from a person carrying out the same functions	**137**	89.0%
Will undertake the duty to act with the general knowledge, skill and experience that they possess	**121**	78.6%
Has not been previously convicted or cautioned for, ill-treatment or neglect	**144**	93.5%
Has not been previously convicted or cautioned for ill-treatment of patients under the Mental Health Act 1998	**140**	90.9%
Has not been previously convicted or cautioned for a serious offence against the person (e.g. murder, manslaughter, threats to kill)	**142**	92.2%
Has not been previously convicted or cautioned for offences under the Sexual Offences Act 1992 or the Criminal Justice Act 2001	**141**	91.6%
Has not been previously convicted or cautioned for crimes including dishonesty, deception, terrorism, money laundering, bribery or misconduct in a public office	**136**	88.3%
Not Answered	**5**	3.3%

DHSC Response:

You told us:	We Will Do:
Across the selection of proposals there was an average of 87.53% agreement to requirements proposed.	Incorporate requirements into Capacity Bill/secondary legislation upon which the Department will publically consult. There were 79 specific responses to this. For reference these are summarised in Appendix 7.

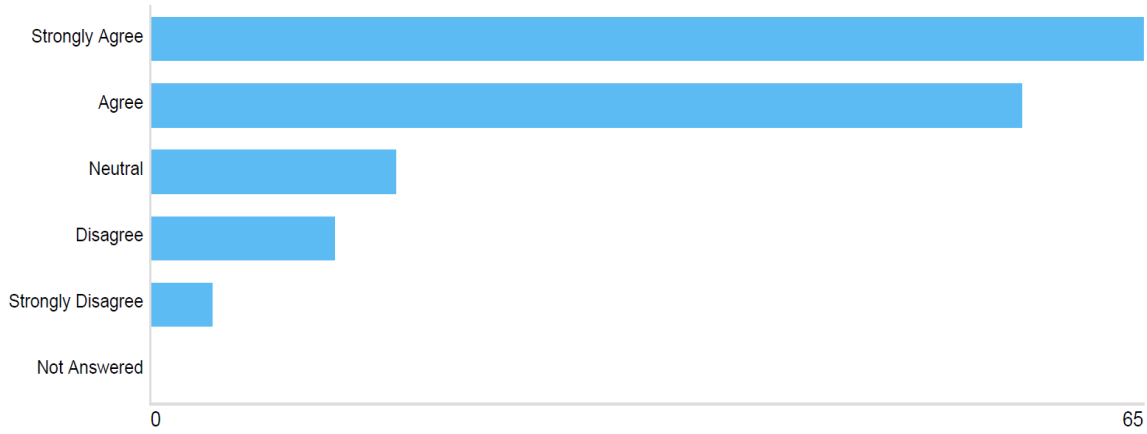
Court Appointments

16. Do you agree with this statement? "Where a person has lost capacity to make decisions and has not appointed a person (Power of Attorney), the Court should have the power to make decisions on a person behalf regarding their health and welfare."

Table 16.1 There were 154 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**65**	42.2%
Agree	**57**	37.0%
Neutral	**16**	10.4%
Disagree	**12**	7.8%
Strongly Disagree	**4**	2.6%
Not Answered	**0**	0.0%

Figure 16.1 Support for the statement where there is no Power of Attorney appointed, Court should have the power to make decisions on a person behalf regarding their health and welfare



DHSC Response:

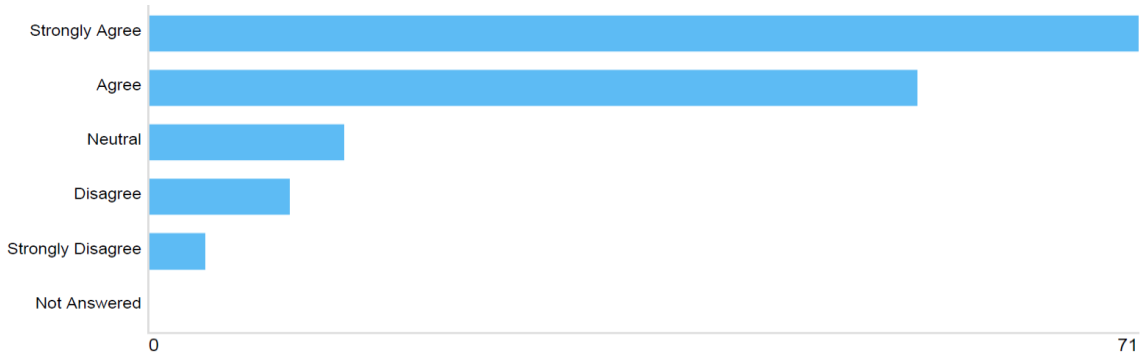
You told us:	We Will Do:
79.22% of responses agreed/strongly agreed	Incorporate Principle in Capacity Bill for consideration

17. Do you agree with the statement: "Where a person has lost capacity to make decisions, the Court should have the power to appoint a person to do so on their behalf regarding their health and welfare"

Table 17.1 There were 154 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**71**	**46.10%**
Agree	**55**	**35.71%**
Neutral	**14**	**9.09%**
Disagree	**10**	**6.49%**
Strongly Disagree	**4**	**2.60%**
Not Answered	**0**	**0.00%**

Figure 17.1 Support for the Court to have the power to appoint a person to do so on their behalf regarding their health and welfare



DHSC Response:

You told us:	We Will Do:
81.81% of responses agreed/strongly agreed	Incorporate this principle into the Capacity Bill

Advance Decisions

18. Do you have any comments on the key characteristics of advance decisions?

This was an open question and there were 73 specific responses to this part of the question which are presented in Appendix 8.

DHSC Response:

You told us:	We Will Do:
20.56% of the comments related to the timing of interventions, capacity test, follow and reviews 18.69% of comments related to communication – accessibility, support and training.	Draft the Bill so that it sets the parameters for advance decisions to refuse treatment, particularly with regard to capacity, the form a decision can be made in, what decisions can be taken and withdrawing from such a decision. Regarding the communication of decisions this will be provided for in the Bill with practical guidance in the Code of Practice. There were 73 specific responses to this. For reference these are summarised in Appendix 8.

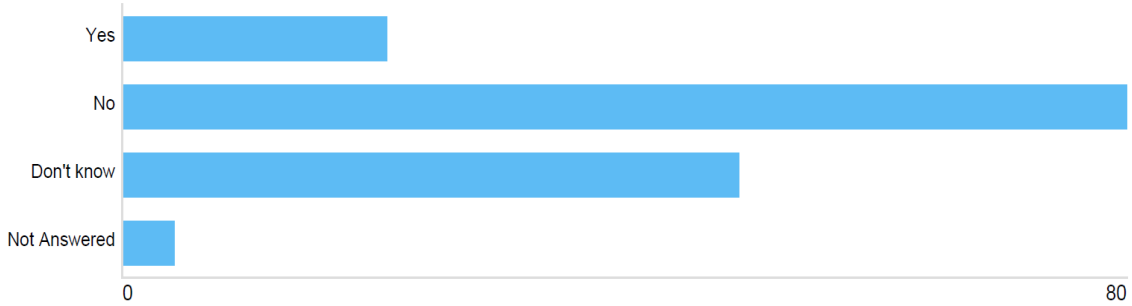
Excluded Decisions

19. This list of excluded decisions mirrors the list in England and Wales. Do you think any other decisions need to be included in the list?

Table 19.1 There were 150 responses to this part of the question.

Option	Total	Percent
Yes	21	13.6%
No	80	52.0%
Don't know	49	31.8%
Not Answered	4	2.6%

Figure 19.1 Response to whether other decisions need to be included on the list of 'Excluded Decisions'



DHSC Response:

You told us:	We Will Do:
51.95% pf responses advise that they do not feel that any other decisions need to be placed on the list,	The response of 'Don't know' and 'Yes' (45.46%) indicate that more clarity is required, a further due diligence will be performed. Fully consider the additional factors raised when developing the draft Capacity Bill, the Code of Practice. There were 21 specific responses to this. For reference these are summarised in Appendix 9.

Ill-Treatment or Neglect

20. Should the Bill include an offence of ill-treatments or wilful neglect in respect of a person with responsibility for the care of a person lacking capacity?

Table 20.1 There were 153 responses to this part of the question.

Option	Total	Percent
Yes	150	97.4%
No	1	0.7%
Don't know	2	1.3%
Not Answered	1	0.7%

DHSC Response:

You told us:	We Will Do:
97.40% would like to see the Capacity Bill incorporate an offence of Ill-treatment or wilful neglect	The Bill will include a provision making it an offence for a person responsible for the care of a person lacking capacity to ill-treat or neglect them.

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21. Do you think the offences of ill-treatment and wilful neglect should extend to organisations as well as to individuals?

Table 21.1 There were 152 responses to this part of the question.

Option	Total	Percent
Yes	146	94.8%
No	2	1.3%
Don't know	4	2.6%
Not Answered	2	1.3%

DHSC Response:

You told us:	We Will Do:
94.81% would like to see offence of ill-neglect or wilful neglect extended to organisations.	Incorporate this principle into the Capacity Bill

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Deprivation of Liberty

22. In England and Wales, deprivations of liberty provisions are extended to hospital and care home settings. The Department is considering introducing legislative provisions to follow the UK and include deprivation of liberty provisions. Please indicate whether you consider that the deprivation of liberty provisions should extend to extend one or more of the following

Deprivation of liberty provisions: Hospital and Care home settings

Table 22.1 There were 150 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**102**	66.2%
Agree	**42**	27.3%
Neutral	**3**	2.0%
Disagree	**0**	0.0%
Strongly Disagree	**3**	2.0%
Not Answered	**4**	2.6%

DHSC Response:

You told us:	We Will Do:
93.50% of responses agreed/strongly agreed	(Information received in this question relating to Deprivation of Liberty was presented in this policy consultation). Fully consider the responses received for the second stage, at which the Department will be legislating with regard to deprivation of liberty.

Deprivation of liberty provisions: Supported Living (Including specialist or adapted accommodation)

Table 22.2 There were 150 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**94**	61.0%
Agree	**45**	29.2%
Neutral	**7**	4.6%
Disagree	**1**	0.7%
Strongly Disagree	**3**	2.0%
Not Answered	**4**	2.6%

DHSC Response:

You told us:	We Will Do:
90.26% of responses agreed/strongly agreed	Fully consider the responses received for the second stage, at which the Department will be legislating with regard to deprivation of liberty.

Deprivation of liberty provisions: Shared Lives (otherwise known as 'Adult placement')

Table 22.3 There were 150 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**88**	57.1%
Agree	**43**	27.9%
Neutral	**15**	9.7%
Disagree	**1**	0.7%
Strongly Disagree	**3**	2.0%
Not Answered	**4**	2.6%

DHSC Response:

You told us:	We Will Do:
85.06% of responses agreed/strongly agreed	Fully consider the responses received for the second stage, at which the Department will be legislating with regard to deprivation of liberty.

Deprivation of liberty provisions: Domestic settings

Table 22.4 There were 150 responses to this part of the question.

Option	Total	Percent
Strongly Agree	**81**	52.6%
Agree	**39**	25.3%
Neutral	**22**	14.3%
Disagree	**4**	2.6%
Strongly Disagree	**4**	2.6%
Not Answered	**4**	2.6%

DHSC Response:

You told us:	We Will Do:
77.92% of responses agreed/strongly agreed	Fully consider the responses received for the second stage, at which the Department will be legislating with regard to deprivation of liberty.

23. Age requirements: When considering provisions regarding advance and deprivation of liberty, should such provisions apply to;

Table 23.1 There were 147 responses to this part of the question.

Option	Total	Percent
16 Years and above	104	67.5%
18 Years and above	43	27.9%
Not Answered	7	4.6%

DHSC Response

You told us:	We Will Do:
67.53% would like the age requirement applied to be 16 years and above	Incorporate this principle into the Bill. There were 21 specific responses to this. For reference these are summarised in Appendix 10.

Independent Capacity Representative.

24. Do you agree with the statement: The Department should introduce, by law the new role of Independent Capacity Representatives?

Table 24.1 There were 152 responses to this part of the question.

Option	Total	Percent
Strongly Agree	95	61.7%
Agree	44	28.6%
Neutral	7	4.6%
Disagree	2	1.3%
Strongly Disagree	4	2.6%
Not Answered	2	1.3%

DHSC Response:

You told us:	We Will Do:
90.26% of responses agreed/strongly agreed	We will progress with legislating for independent capacity representatives.

Other

25. Do you have any additional comments or feedback relating to the proposed Capacity policy?

1. There are 55 comments provided with permission to publish; these are presented in Appendix 11.

DHSC Hard to Reach – Informal Additional Consultation Feedback

2. The DHSC responded itself in respect of addressing the "hard to reach" individuals who because of their current mental capacity or learning disabilities may not be able to fully participate in the online consultation. The purpose of an individual focus group discussion was aimed at enabling equality of opportunity for everyone who lives, works in or visits the Isle of Man.

Hard to reach is defined as communities or individuals whose voices are seldom heard or recognised in a formal structured approach to consultation.

The purpose behind the consultation being completed outside the parameters of the public consultation is to ensure that equality duties are facilitated effectively, ensuring that the Department communicate accessibly with people.

Due to the complexities involved in communicating with vulnerable persons. It was felt that it was best to have a continued consultation process with 'hard to reach' persons which will both feed into the Policy and the Bill consultation and ultimately the Codes of Practices but in an informal way, capturing and insight into participants feelings and views.

Policy Consultation Informal Consultation: Hard to Reach Autumn 2020

A. Groups of 'hard to reach' who were consulted – several individuals from the following groups:
1. Adults with learning disabilities
2. Adults with autism

B. Consultations were conducted by 1-2-1 meetings and facilitated by conversation rather than direct question answers.

C. They were consulted on the following topics:
1. The type of decisions which are most important to the individuals
2. What helps and hinders decision making
3. Who would you want/need to help you make decisions
4. Unwise decisions – own and other people's
5. What are your experiences of being stopped from doing what you want
6. How did you feel?

Table 25.1 DHSC Informal Hard to Reach Consultation - Summary of responses

Independent Representatives is important - Family input essential, who, what, when
You said: Whilst not everyone had the same priorities in terms of support, the majority of people spoken to expressed a desire to be supported to make key decisions. Families and support staff were the most commonly identified people to help with decision making.
Effect of drugs, medical condition, disability effecting capacity. **Communication - accessibility, support and training - Mechanism and procedures for challenge. - Timing of intervention, capacity test, follow up, reviews**
You said: These themes could not be explored with everyone, but for some people (especially those with autism) the need to arrive at a decision in one's own way was a clear priority. Undue time pressures, challenges to a person's decision making process, and hostile environments were cited as especially frustrating. In some cases it was clear that people did not feel included in major decisions about them. When asked what would have improved the situation it was said that had things been explained to them properly they would have been far happier.
Best interest, previous stated wishes, individual needs - Risks /impacts
You said People were split on this. The majority of people spoken to felt that some limits on poor decision making might be appropriate. However, there was a clear distinction between the unwise decisions which people made for themselves; and those that other people made. In general there was a far higher tolerance for one's own unwise decisions as essential for happiness, and the decisions of others which were viewed negatively. For example, smokers tended to defend this choice quite robustly, whereas non-smokers were often of a view that it could or should be restricted. There were also a smaller number of people who took a more extreme position that there were no grounds for curbs on unwise decisions. When explored it was clear that a degree of ownership over unwise decisions, and this was linked to opportunities for learning and growth. These views were more prominent in those with higher levels of independence.
Coercion, neglect, abuse
You said This was again difficult to explore with everyone, but there was some strong objection to 'meddling' from outside parties. People's experiences were different; for example some people felt that they had more freedom in a care setting, whereas others felt they had less. It was clear that interference other than what was felt to be supportive was not welcomed

Hard To Reach: Consultation Overview

It was clear from the sessions that everyone spoken to was an individual, with their own views and experiences. The views presented are representative of select members of hard to reach groups, but cannot be represented as representative of the groups as a whole. Nevertheless, it was clear that the freedom to choose was important to everyone, and this was particularly evident when linked to the choice of something generally regarded as a treat or vice.

Most of the conversations served to validate the general approach that is being taken. Whilst the views of many are yet to be established, it is reassuring that there is support for the approach from some of those most likely to be impacted by the proposed changes. What is also evident is that the best practice guidance currently in place in the absence of a law has not been sufficient to meet the needs of everyone on the island, with several people recalling experiences where they were excluded from major decisions, or did not have matters explained to them. It was also pleasing to see that this was the exception rather than the norm.

Appendix 1: Summary of Our Response

(Note Q1 -2 consultation administration questions only)

A) Summary of questions and outcomes:			
	Question	**You told us:**	**We Will Do:**
Q3	May we publish your response?	29.22% said - Yes, you can publish my response in full and 54.55% said - Yes, you may publish my response anonymously	
Q6	Do you agree that specific legislation to assist with Capacity issues is required on the Isle of Man?	95.45% agreed that specific Legislation is required	Develop a Draft Capacity Bill upon which we will publically consult.
Q7	The name of the Isle of Man Act is proposed as 'The Capacity Act'. In England it is called the Mental Capacity Act and in Scotland the Adult with Incapacity Act. Please choose one of the following, or recommend an alternative name.	The majority would like Legislation to be called the Capacity Act	The Department will call the Act The Capacity Act
Q8	Capacity Test - Do you agree with proposed test to decide whether a person is unable to make a decision for themselves?	Majority 86.06% agree with the proposed test principles	The proposed Capacity test will be incorporated into the Capacity Act
Q9	Capacity Test - Do you think anything else should be taken into consideration to decide whether a person is unable to make a decision for themselves? (If yes, what else should be considered: There were 92 responses to this part of the question)	Majority 56.49% felt more factors should be taken into consideration, added to the 11.04% who are unsure if there is a need for more protections. Of the 67.53% who felt there was possible need for additional safeguards. 16.92% felt that Independent representation was important also 16.92% felt that timing of intervention, follow up and reviews was important.	Fully consider all the additional factors that have been raised when developing the draft Capacity Bill and the Code of Practice.
Q10	Best Interests - Do you think there should be any additions to this list of rules? (If yes, what else should be added: There were 44 responses to this part of the question)	Whilst 53.25% agreed that the best interest rules proposed were adequate, 23.38% who advised they thought additions were needed. 28.03% of comments indicated that independent representation is important 16.98% feeling that communication, accessibility, support and training individual needs and previous stated wishes are important.	Fully consider the additional factors raised when developing the draft Capacity Bill, the Code of Practice. In particular the processes and procedures that will be put in place to monitor actions to reassure the public that the rules agreed to in principle are applied with concerns identified safeguarded.

	Question	You told us:	We Will Do:
Q11	Best Interests - Do you agree with our proposal that additional weight should be given to the wishes of the person lacking capacity? (Any additional comments: There were 35 responses to this part of the question)	88.31% agreed that additional weight should be given to wishes of the person lacking capacity. Within the comments section 17.64% expressed concern about the risks or impacts of decisions made by vulnerable person.	Make it clear on the face of the Act that additional weight should be given to the wishes of the person lacking capacity
Q12	Powers of Attorney - Do you agree with this statement : 'A person with capacity should be able to appoint someone else to make health and welfare decisions for a time when they can no longer make these decisions themselves'	92.86% agreed that a person should be able to appoint a representative	To make provision in the Bill allowing for persons to make powers of attorney concerning health and welfare decisions.
Q13	Powers of Attorney - Do you think the safeguards that we are proposing go far enough to protect donors from potential problems with a Lasting Power of Attorney? (Do you think anything else should be covered? There were 61 responses to this part of the question.)	38.31% agreed that proposed Lasting Power of Attorney safeguards suffice; However, 55.85% indicate that more safeguards are required. These safeguards were indicated in the comments section where Primary concerns related to 19.38% feeling Independent representation is important and 16.32% were concerned about coercion, neglect or abuse opportunities.	Fully consider all the safeguarding concerns raised and as to how they can be met when developing the draft Capacity Bill and the Code of Practice
Q14	Donees - Do you think there should be minimum requirements applied for someone to be able to act as a donee?	91.56% agreed that there should be minimum requirements for someone to acts as donee.	Minimum requirements as to who can act as a donee will be provided for in the Capacity Bill or in secondary legislation which will be subject to public consultation
Q15	Donees -If so, which of the proposed requirements do you agree with? (Any other comments or do you have any further proposed requirements? There were 79 responses to this part of the question.)	Across the selection of proposals there was an average of 87.53% agreement to requirements proposed. Within the comments 18.88% were concerned about coercion, neglect abuse opportunities and 18.10% concerned about the risks/impacts of excluding relatives who fall below requirements and/or decision made by vulnerable person, with concerns about family input and time limits and ability to challenge to be defined.	Incorporate requirements into Capacity Bill/secondary legislation upon which the Department will publically consult. The Department has also noted the "other comments" raised with regard to minimum requirement and will be considering what should go in the Bill now and what could go in secondary legislation under the Bill at a later stage.

	Question	You told us:	We Will Do:
Q16	Court Appointments- Do you agree with this statement? "Where a person has lost capacity to make decisions and has not appointed a person (Power of Attorney), the Court should have the power to make decisions on a persons behalf regarding their health and welfare."	79.22% agreed/strongly agreed that a court should have the power to make decisions in the circumstances described.	Incorporate this principle into the Capacity Bill.
Q17	Court Appointments- Do you agree with the statement: "Where a person has lost capacity to make decisions, the Court should have the power to appoint a person to do so on their behalf regarding their health and welfare"	81.81% of responses agreed/strongly agreed that a court should have the power to appoint a person to act on behalf of a person who has lost capacity.	Incorporate this principle into the Capacity Bill
Q18	Advance Decisions- Do you have any comments on the key characteristics of advance decisions? (There were 73 responses to this part of the question)	20.56% of the comments related to the timing of interventions, capacity test, follow and reviews 18.69% of comments related to communication – accessibility, support and training.	Draft the Bill so that it sets the parameters for advance decisions to refuse treatment, particularly with regard to capacity, the form a decision can be made in, what decisions can be taken and withdrawing from such a decision. Regarding the communication of decisions this will be provided for in the Bill with practical guidance in the Code of Practice.
Q19	Excluded Decisions- This list of excluded decisions mirrors the list in England and Wales. Do you think any other decisions need to be included in the list? (If yes, what else should be considered? There were 21 responses to this part of the question)	51.95% of responses advise that they do not feel that any other decisions need to be placed on the list. Comments section reflects potential need for some flexibility and the interrelated aspect of Capacity Act and 22.72% applicable to Safeguarding.	The response of *'Don't know'* and *'Yes'* (45.46%) indicate that more clarity is required, a further due diligence will be performed. Fully consider the additional factors raised when developing the draft Capacity Bill, the Code of Practice.
Q20	Ill-Treatment or Neglect- Should the Bill include an offence of ill-treatments or wilful neglect in respect of a person with responsibility for the care of a person lacking capacity?	97.40% would like to see the Capacity Bill incorporate an offence of Ill-treatment or wilful neglect	The Bill will include a provision making it an offence for a person responsible for the care of a person lacking capacity to ill-treat or neglect them.

	Question	You told us:	We Will Do:
Q21	Ill-Treatment or Neglect- Do you think the offences of ill-treatment and wilful neglect should extend to organisations as well as to individuals?	94.81% would like to see offence of ill-neglect or wilful neglect extended to organisations.	Incorporate this principle into the Capacity Bill
Q22	Deprivation of Liberty- In England and Wales, deprivations of liberty provisions are extended to hospital and care home settings. The Department is considering introducing legislative provisions to follow the UK and include deprivation of liberty provisions. Please indicate whether you consider that the deprivation of liberty provisions should extend to extend one or more of the following	Deprivation of liberty provisions: 93.50% of responses agreed/strongly agreed- Hospital and Care home settings. 90.26% of responses agreed/strongly agreed - Supported Living 85.06% of responses agreed/strongly agreed - Shared Lives 77.92% of responses agreed/strongly agreed - Domestic settings	(Information received in this question relating to Deprivation of Liberty was presented in this policy consultation). Fully consider the responses received for the second stage, at which the Department will be legislating with regard to deprivation of liberty.
Q23	Deprivation of Liberty- Age requirements: When considering provisions regarding advance and deprivation of liberty, should such provisions apply to; (Additional comments: There were 21 responses to this part of the question)	67.53% would like the age requirement applied to be 16 years and above	Incorporate this principle into the Bill.
Q24	Independent Capacity Representative- Do you agree with the statement: The Department should introduce, by law the new role of Independent Capacity Representatives?	90.26% of responses agreed/strongly agreed with requirements to introduce in Law the requirement for a new role of Independent Capacity Representative.	We will progress with legislating for independent capacity representatives.
Q25	Other- Do you have any additional comments or feedback relating to the proposed Capacity policy? (There were 65 responses to this part of the question.)	65 responded to this opportunity to submit any comments or feedback relating to proposed Capacity Policy. Within the comments and responses 17.52% related to Independent Representatives being important and 21.64% identified that communication, accessibility, support and training across all stakeholders was important.	A robust Code of Practice will be formulated ensuring requirements are communicated; accessibility, support and training are open and transparent.

Appendix 2:

A) Summary of Common Themes recognised throughout the consultation additional <u>comments</u> sections:

	You told us:	**We Will Do:**
1.	Independent Representatives are important	Create the role of Independent Capacity Representatives under the Capacity Bill.
1.a	Family input essential, who, what, when	We will ensure that Code Of Practice (COP) and subsequent process and procedures clarifies who, what, when, how.
2.	Effect of drugs, medical condition, disability effecting capacity.	The Code of Practice will incorporate information gathering as part of Capacity Act requirements to have reason to doubt capacity and if a decision making can be delayed if capacity is expected to resume.
3.	Communication - accessibility, support and training	Ensure adequate information, communication strategies and adaptations to the person's needs are within the Code of Practice. Open and transparent resilient procedures and training requirements.
3a	Mechanism and procedures for challenge.	Processes to be considered to be included within the Bill.
4.	Timing of intervention, capacity test, follow up, reviews	Language within the Bill to be considered It could be possible to have wording in the act to manage, partially, variability, temporary incapacity and coercion.
5.	Best interest, previous stated wishes, individual needs	Best interest will be protected within the legislation and vigorously applied by Legislation, Code of Practice, Communication practices and implemented procedures Openness and transparency of decision making on behalf of a vulnerable person and record keeping Comments regarding the nature of the test – confirmed in draft COP to aid the consistent application of the test to a range of different decisions/circumstances Thresholds for decisions – There were some concerns raised from those with experience in the UK (and in the consultation) about over complicating minor day to day decisions, and whether or not this properly sits here. COP will probably address this, but again the question was whether or not this needs to be more explicit to ensure that the provisions are targeted where they are intended.
5.a	Risks /impacts	These will be robustly included in Risk Assessments by the responsible person. Incorporate requirements within the COP with procedures applicable to service areas as part of best practice.

	You told us:	We Will Do:
6.	Coercion, neglect, abuse	Propose new offence of ill treatment and/or wilful neglect and extend the new offence to organisations as well as individuals.
7.	Living Will integration.	The Bill will legislate for advance decisions/living wills.
10a	Safeguarding	A number of comments were made in respect of safeguarding the individual; some included the identified need to ensure protection from coercion (a theme) and other concerns that are likely to constitute abuse. To be examined further – possibly in COP.
10b	Access to records and legal documents Concerns about Data Protection issues arising, authority, notification etc.	Complete a due diligence exercise to ensure that legislation and COP meet the requirements of confidentiality and data protection.

APPENDIX 3: Question 9:

Table 9.2 Sample of matters identified that maybe considered when deciding whether a person is unable to make a decision for themselves?

Q9 You told us:	DHSC Response:
Any Medical conditions, treatments or illicit substances that can impair capacity should be monitored to help assess if they have any bearing on the capacity of the individual *(George Pressley)*	In relation to reasons a person may lack capacity a Code Of Practice will facilitate this concern, plus training, and assessment documentation.
Is capacity fluctuating and/or can the decision be delayed until capacity returns? Can the information on which the decision is made be provided in a different way? *(Stephen Buttery)*	In respect of fluctuating and decision delay this is dealt with in Clause 6 – when determining best interest. In respect of provision of information this is dealt with in Clause 5(2). Code Of Practice will facilitate, plus training, and assessment procedures and documentation.
Carers insight is often valuable as some mental health patients are often good communicators but have little insight	Code Of Practice will facilitate this need
There are many things that I believe need to be considered and I could make a very long list in relation to the same however for now the main things I think should be first and foremost on that list is the consideration of the medication a person is taking, how much, when last taken, if any is due and are they withdrawing. Having a full and complete capacity test taken by a qualified consultant and not a Dr who could easily be duped by a family member or other person who could have ulterior motives in mind, an end game! *(Bridget Carter)*	Code Of Practice will facilitate this need Assessor appropriate to the decision being taken. Plus training, monitoring, assessment procedure and documentation.
They should be in a recognised environment where they feel comfortable. With people they trust. This will give them an environment where their capacity can be properly identified.	Code Of Practice will facilitate this requirement
As long as in best interests and capacity is reviewed for remediable short term capacity issues on regular basis	Code Of Practice will facilitate this requirement
It is essential that a in the case of a blind or visually impaired person that capacity assessments are undertaken in a manner which matches their preferred communication format , clearly this is particularly important when information used in the process of assessment includes printed material	Code Of Practice will facilitate these needs
My example is: if a person with dementia wishes to wear a different outfit. They may not understand the information relevant to the decision but it is their right as an individual to choose their clothes (Human Rights Act "peaceful enjoyment of their possessions"). The onus is on their carers to ensure that this is properly adhered to.	Code Of Practice will facilitate this need. The Bill will be drafted to be compatible with the Human Rights Act 2001 (which incorporates the rights set out in the European Convention on Human Rights)
Is it possible that persons from other countries where English is not their first language may revert back to their mother tongue if suffering from mental or physical incapacity?	Code Of Practice will facilitate this need
Those with other disabilities like for example Autism or Downs Syndrome or mental health issues	These would be considered, but functionality remains the key.
Decision by qualified doctor only	Decision maker depends on the decision – may be a doctor, but only where required – proportionality is important.
What is in their "Best interests" as deemed clinically but with input from family/friends/carers	Code Of Practice will ensure this is considered and facilitated
Whether they can fully comprehend the consequences of their decision, and how this may positively or negatively impact them or others *(Robert Juan Greggor)*	This will be explicit in law in Clause 5 and Code Of Practice will facilitate risk assessments
There should be some clarification that just because their decision seems strange, not in their own best interest or you disagree with it, that does not determine their capacity.	This will be explicit in law within Clause 3(4) and Code Of Practice will facilitate enforcement on assessor.
Consideration must be taken to ensure this is not simply a temporary loss of capacity. In which case the decision should be delayed until capacity is regained (unless life threatening of course).	This will be explicit in law by Clause 6(3) and facilitated via a Code of Practice

Q9 You told us:	DHSC Response:
Medical and social input. Not just the relative/ carer.	This will be explicit in law and facilitated via Code of Practice Stakeholders involved in direct care will be provided relevant and proportionate information,
In the wording of the test above, is it appropriate and clear to specify 'any ONE' of the following (4) alongside the linking word AND between each? Could this not give rise to unnecessary challenge about the definition of test 2? *(Andrew Cole)*	legislatively the clause as worded works, possibly merit for the reader to add in "any one"
I feel weight should be given to known previous wishes and wants as well as current wishes and wants from the individual.	Code Of Practice will ensure this is considered and facilitated
People who like me have no close relatives should be encouraged to make a WILL, and A Living WILL My own advocate drew up a living will for me which gives clear instructions to the Medical People on what to do about me and who to contact . Have put copy on wall at home in case I am found dead or very ill. I am stage FIVE of double kidney failure so my days are numbered , There are a lot of people that would have to be officially informed of my death or sudden illness such as CVA, as well as plan and buy their funeral	Advanced decisions facilitate Living Will – Guidance and Code of Practice will assist with implementation and communications needed.
The person who knows them best, if appropriate, a best interest, meeting taking into account the views and opinions of those closest to the individual. The test should be carried out several times, not just once, to ensure the person has capacity or not i.e. stroke or ABI can delay the brain processing information and the person may not be able to answer immediately but needs time.	Code Of Practice to ensure this is facilitated. Accurate and contemptuous record keeping, proportionate and only relevant sharing of information held on the individual can be shared.
Whether they are victims of coercive behaviour where the perpetrator(s) are their partners, family, neighbours or local community. *(Matt Devereau)*	Safeguarding considerations required.
The person must be deemed capable to make decisions without putting their own or others' lives at risk. For example taking illegal drugs, driving whilst medicated/hallucinating.	Behaviours which present a risk to others can also be addressed under different legislation.
Pain can affect capacity, so (ONLY IF there is the likelihood of pain relief resolving this), the assessment shout be delayed until pain is managed or it is accepted that pain cannot be managed to a level where capacity is not affected	Code Of Practice will ensure this is facilitated and considered appropriately
The impact the decision is going to have an the person or persons close relatives	Code Of Practice will ensure these risk assessments are facilitated
It would be useful for Independent Advocacy to be included where applicable to help discuss and determine understanding. For a balanced decision to be made in relation to capacity it is important that every opportunity is given to rephrase and simplify questions to be absolutely sure that every attempt has been made to properly assess understanding and cognition. *(Jayne Sloane- Crossroads)*	The Department is proposing to create the role, in legislation, of independent capacity representatives to afford appropriate provision for help and representation for people who lack the capacity to make important decisions who may not have family or friends that it would be appropriate to consult.
Instead of.....they must be able to use and weigh that information to arrive at a choice... they must be able to balance choice with risk....	The right to make unwise or risky choices will also be protected. That does not mean that carer will not try and encourage safer choices
The fact that capacity is fluid and can vary from time to time and be different from one type of decision to another.	In respect of fluctuating and decision delay this is dealt with in Clause 6 – when determining best interest.
Capacity testing as outlined above does not make it clear is power of attorney has been competently completed for the subject under scrutiny or whether this is some form of 'sectioning'. If there is a power of attorney then the 'donee' should remain able to act within the permissions granted in said instrument (including acting without lodgement of the instrument at Court if that is what the donor instructed. If there is no valid power of attorney then the tests proposed are reasonable. *(D. Varley)*	Further consideration will be progressed by the Legislation drafter
People with short term memory loss may not be able not be able to perform well in the test above but may be able to continue to make good decisions about things they have routinely done all their life.	Code of Practice will incorporate and manage procedures applicable to variability
Stage 2 point 4 states that "someone must be able to communicate their decision whether by talking, sign language or any other means." It is critical that all information is provided in the person's preferred medium of communication and/or language. This has not been made clear in points 1-3.	Code of Practice will outline requirements and assistance in facilitating and accessibility of communication methods to assist ALL

Q9 You told us:	DHSC Response:
Circumstances can change according to the health and mind-set of the person - an individual with epilepsy, for example, could be better able to cope on some days than others. As could someone dealing with substance abuse, depression or other medical conditions	Code of Practice will incorporate and manage procedures applicable to variability
Have all avenues been explored before decisions have been made, and has this been done independently	This will be explicit in legislation and the Code of Practice.
We do not like the wording of the first stage test and it should include the word valid. Also some indication of mental impairment or disorder which impacts on their ability to make decisions. *(Adult Generic Team)*	Wording confirmed in draft
(a) Capacity must be assumed unless shown otherwise (b) Decisions which would appear to be unwise do not mean lack of capacity *(NHS Independent Review Body)*	These principles will be Explicit in Law and enforced via application of a robust Code of Practice.

Within the 92 responses received. there were 130 identifiable elements related to the following themes:

1	Independent Representatives is important	(16.92%)
1a	Family input essential, who, what, when	(6.15%)
2	Effect of drugs, medical condition, disability effecting capacity.	(16.15%)
3	Communication - accessibility, support and training	(15.38%)
4	Timing of intervention, capacity test, follow up, reviews	(16.92%)
5	Best interest, previous stated wishes, individual needs	(9.23%)
5a	Risks /impacts	(2.3%)
6	Coercion, neglect, abuse	(11.53%)
10a	Safeguarding	(5.38%)

APPENDIX 4 Question 10 Best Interest Test

Table 10.2 The following are a summary of responses for additional rules for Best Interest Test. There were 44 responses to this part of the question.

Q10 Samples You told us:	DHSC Response:
What will happen with existing EPoA's? The decision maker (s) need to be the correct people. i.e. if the decision is for dental treatment then the dentist should be at the best interests meeting. There should always be someone independent to represent the person. An independent mental advocacy service should be in place. *(Stephen Buttery)*	EPA will be retained. It is proposed that the provisions of the Capacity Bill will repeal and replace the provisions of Part 7 of the Mental Health Act 1998 and the Powers of Attorney Act 1987 however existing EPA's will continue to be recognised. Code of Practice will facilitate approach proportionate to decision making needs.
Carers should be automatically on lists especially if patients are paranoid and lack insight	Presumption of involvement, not absolute (excluded where appropriate)
Persons Gp	As appropriate
Before my mother became incapacitated she had made a Living Will where she stated that she didn't want lifesaving intervention that would merely prolong an end of life situation. She had had a stroke and my brother and I were made to consider the situation where we could have gone against her wishes. This was a horrible position to be placed in. We knew her wishes but had to say that we didn't want lifesaving intervention. We knew that that was what she wanted. Why didn't the doctors accept her wishes?	Advanced decisions facilitate Living Will – drafter to ensure ease of reference to the two comparable concepts.
They're next of kin. *(Sonia Fargher)*	
LPA, should like the UK be separated into medical and financial, then the LPA can be consulted as the legal medical representative. The current system needs reviewing. *(Fiona Smith)*	These elements will be Explicit in law, the provisions re powers will mirror like provisions in the Mental Capacity Act 2005 (Parliament)
D) to ensure that the opportunity is provided and to encourage each individual to participate in the decision.	Explicit in law, clause 6(4) which states that D must, so far as reasonably practicable, permit and encourage P to participate, or to improve P's ability to participate, as fully as possible in any act done for P and any decision affecting P
You are already requested to consider Do Not Resuscitate so the list of best interests would be beneficial. The key is ensuring this information is shared with person named as the "to be consulted". Often these nominees do not have regular contact.	Do Not Resuscitate (DNR) is not in the scope unless it is an advanced decision
f. should be changed as "if it is possible" may be used as a get out clause. Anyone who comes forward with relevant information connected to the person. Reviewing decisions when put in place on a regular basis. to be able to change, amend or reverse a decision. - This would be relevant to a recoverable illness.	Onus will be on decision maker to evidence why it was not possible. If decision had to be made imminently then there may be a need for this caveat. Code of Practice will define capacity assessment documentation to mitigate.
Probably but can't think of any pressing ones at the moment!	
is the person concerned family resident on the Isle of Man also, have they been previously, why they are not resident (is the individual concerned escaping an abusive family relationship)	Code of Practice will incorporate process to evaluate and trigger safeguarding
A catch all clause should be added " together with any other matter reasonably considered to be in the donor/patients best interests " this would cover any eventuality and prevent the need for an exhaustive list of requirements *(Jerry Carter – Carter Advocates)*	This concept would be at odds with key principles
Where disagreement between the one deemed to be lacking capacity, and a carer happens this may unduly affect the capacity to be as independent as they could be.	Code of Practice will assist in such situation.
Any further information that is relevant should be considered and this should be done on a case by case basis to make best interest decisions. *(Jayne Sloane- Crossroads)*	Code of Practice will provide recommendations for individuals and carers to prepare and facilitate ensuring their needs are met IF required by having Accurate and contemptuous record keeping, proportionate and relevant sharing for direct care of the patient service user will be facilitated.
I think its ok and covers the topic but I'm not 100% sure	
The keeping of good records, the participation of the person and consulting with those close to him are paramount but the views of the person should, where possible, take precedence. *(David S Gawne - Third Sector Official/Trustee)*	Accurate and contemptuous record keeping, proportionate and relevant sharing for direct care of the patient service user, patient/service users wishes etc. recorded in record – will be articulated in Coe of Practice

Q10 Samples You told us:	DHSC Response:
I think its ok and covers the topic but I'm not 100% sure	
Factors that may influence the decision should be specified e.g. a decision may have operational/resource implications for services or a practical/financial impact on family members. It is important to acknowledge that there may be conflicts of interest.	Code of Practice will define and the Department is proposing to create the role, in legislation, of independent capacity representatives to afford appropriate provision for help and representation for people who lack the capacity to make important decisions who may not have family or friends that it would be appropriate to consult.

Within the 44 responses received. there were 53 identifiable elements related to the following themes:

1.	Independent Representatives is important	(28.3%)
1.a	Family input essential, who, what, when	(9.43%)
3	Communication - accessibility, support and training	(16.98%)
4	Timing of intervention, capacity test, follow up, reviews	(9.43%)
5	Best interest, previous stated wishes, individual needs	(16.98%)
5.a	Risks /impacts	(1.86%)
6	Coercion, neglect, abuse	(11.32%)
7	Living Will integration.	(3.77%)
10a	Safeguarding	(1.86%)

APPENDIX 5 Question 11:

Table 11.2 Additional weight given to the wishes of the person lacking capacity

Any additional comments: There were 35 responses to this part of the question.

Q 11 You told us:	DHSC Response:
I think your outcome should be based on statutes, bills etc. in place around the world and not just England, Scotland or Wales! A lot of American legislation originally came from English legislation, yet seems somehow to have been lost in translation and still going in America. *(Bridget Carter)*	Due Diligence has been completed assessing various jurisdiction Capacity legislation.
Where the additional weight is gained from an advance decision appropriately documented when the patient DID have capacity	Will be Explicit in Law and Code of Practice procedures.
The wishes of the person who may be lacking capacity should always come first (Human Rights Act).	The Bill will be drafted to be compatible with the Human Rights Act 2001 (which incorporates the rights set out in the European Convention on Human Rights)
This would vary dependent upon their condition.	
However, in some instances, there may be occasions where the degree of incapacity is such that the individual's wishes are unachievable/unrealistic and there needs to be clear, unambiguous mechanism as to how these will be dealt with.	Code of Practice and support for carers will assist these situations
consideration should be given to previous wishes and lifestyle choices before capacity was lost	This is Explicit in law clause 6(6) – best interests D must consider, so far as is reasonably ascertainable P's past and present wishes and feelings. and will be incorporated in Code of Practice
The fact of loss of capacity does not change the wishes, likes and dislikes of the patient in my experience, subject to other overriding factors, to all extents possible these should be respected *(Tim Henwood – Legal Professional)*	The Department is fully supportive of ensuring a person's wishes are respected and facilitate where possible
If the person has now lost capacity, but previously has stated (ideally documented) their wishes, then this is a very strong additional weight which should be the leading decisive factor.	Advanced decision will be respected in clause 6(6) of the legislation and Code of Practice will facilitate.
……..Including a decision-making flow chart in the Code of Practice would be a useful and practical way of ensuring that there is clarity around best interest decisions. A good example that could be adapted can be found from the British Medical Association's guidance on Clinically Assisted Nutrition and Hydration - https://www.bma.org.uk/media/1162/bma-clinically-assisted-nutrition-and-hydration-canh-decision-making-flowchart.pdf *(Upeka de Silva - Compassion in Dying)*	Comments welcomed and recommendation will be utilised in construction of Co de of Practice
It is important to establish, if possible, if the wishes of the person are being unduly influenced by others and mitigate against this risk.	Code of Practice and safeguarding considerations further required.
Absolutely! Self-determination should be fundamental to this legislation.	

Within the 35 responses received, there were 51 identifiable elements related to the following themes:

1.	Independent Representatives is important	(7.84%)
1.a	Family input essential, who, what, when	(5.88%)
2	Effect of drugs, medical condition, disability effecting capacity.	(1.96%)
3	Communication - accessibility, support and training	(3.92%)
4	Timing of intervention, capacity test, follow up, reviews	(13.72%)
5	Best interest, previous stated wishes, individual needs	(23.52%)
5.a	Risks /impacts	(17.64%)
6	Coercion, neglect, abuse	(13.72%)
7	Living Will integration.	(5.88%)
10a	Safeguarding	(5.88%)

APPENDIX 6 Question 13

Table 13.2 Do proposals go far enough to protect donors from the potential problems with Lasting Power of Attorney; Do you think anything else should be covered?

There were 61 responses to this part of the question.

Q13 You told us:	DHSC Response:
If LPoA loses capacity or proves to not be acting in the person best interests, what happens? Can an LPoA live off the Isle of Man and in a different jurisdiction?	Capacity Bill will reflect current position in existing Manx law under the Power of Attorney 87 Nothing preventing a donee living off-Island
A living will could be in place beforehand, then everyone would understand the views of the person and abide by their wishes should the worst happen.	Advanced decision under relevant section of Capacity Bill.
I feel that there should be more than one person appointed to the LPA role. If there is only one legally appointed LPA, who may have vested interest in the person's well-being, this may influence their decision making process. *(Sonia Fargher)*	Checks and balances to mitigate. Explicit in law and Code of Practice to strengthen The Bill as presently drafted allows a donor to appoint 1, 2 or more.
Constant reasonable review of lasting power of attorney and the level of capacity an individual has and consideration of reversal of it and / or a clause to enable a change of donor - also what would be the process should the donor lose capacity or die?	Some aspect will be explicit in law. Code of Practice will clarify.
There is no reason to remove the current system of an Enduring Power of Attorney, they offer excellent protection for those who have capacity and can be implemented at very short notice, i.e. pending emergency surgery. The LPA system in the UK has hugely increased costs and delay. Additional safeguards could be implemented for an LPA for health, whilst leaving the EPA for property and financial affairs as it stands. *(David Clegg)*	Enduring Power of Attorney is retained in legislation
Witness to Lasting Power on Health matters should be a medical practitioner or legal adviser. *(Jackie Lynch)*	Witness will be specified in law. The Bill is currently worded so that the person witnessing the making of an LPA must be a person able to assess the capacity of the person making an LPA.
Consideration should be given to ensure there was no coercion or pressure involved when drawing up LPA.	Safeguarding and Code of Practice will be in place to ensure protections.
You could consider forever but there will always be one ruthless person who tries to take over another life. the person assessing capacity should be medically trained and not legally trained. They should also have known the person for some time.	Safeguarding and Code of Practice will be in place to ensure protections.
Make sure somebody (plural) knows that a POA exists ... and that it is accessible when required. Sparked by this survey we had the conversation "I am sure we have POAs but where are they are, the when & why, and who has POA .... ridiculous I know, but true."	Guidelines will be issues to public
i think it needs to be clear as to why can assess the capacity of the individual at that time. it should also make links to the person not appearing to be under coercion and control in undertaking this.	This will be explicit in law Code of Practice will mitigate these risks.
It depends what the criteria are for and who the person should be assessing capacity. In law, it is often the duty of an advocate to assess capacity and in some areas there are cases where the ability of a lawyer to assess capacity carries more weight than a medical practitioner. In the Isle of Man I have experienced more and more a reluctance on the part of GP's to provide mental capacity assessments and the NHS professionals are so over worked that reports and assessments are taking more than six months to arrange. In my view, if you require a professional or layman to assess, firstly the criteria should be clearly laid out and arrangements need to be in place that the issue of capacity are speedily resolved within days, even *hours (Tim Henwood-Legal Professional)*	Code of Practice ensure support is clearly provided and in a timely manner.
There should be a clause which enables the Lasting Power of Attorney to be rescinded if the donee is proved to be not acting in the best interests of the doner. I have an aunt now deceased who had two children. My aunt developed Alzheimer and needed care. Her son wanted the best care possible for his mother the daughter wanted to conserve her mothers' estate to the detriment of her mothers' welfare. Fortunately the court of protection got involved and ruled against the daughter. If the daughter had had a lasting power or attorney my aunt would have spent her last few years in misery.	This will be explicit is law and facilitated in Code of Practice

Q13 You told us:	DHSC Response:
Instead of....aged 18 or over and is not the person being appointed to make the decisions Make this aged 18 or over and is not the person being appointed to make the decisions or a relative of this person.	Independence of the witness to be raised with Legislation Drafter.
There will always be exceptional circumstances which cannot be completely covered by legislation so a degree of flexibility is required. *(Margaret Mansfield)*	
These NEED to be tested out on fictitious / real, known cases - with personal details removed to ensure their adequacy and safety and that they fully represent that person in a holistic fashion. *(R W Henderson, MLC)*	Due Diligence in Professional Working Groups have and will continue to be performed in development of Policy, Bill, Code of Practice, operational processes and procedures and risk assessments.
The witness should be a completely independent person ... not someone related to or befriended by the person appointed to make decisions	Code of Practice will outline criteria and checks Independence of the witness to be raised with Legislation Drafter.
they could be put into care home , their house sold that would leave them very unprotected against deception, theft. etc. I would like to see a seconded person name on a lasting power of Attorney and together they must agree what is in the person best interest. *(Maggie Hardinge)*	To fully consider when developing the draft Capacity Bill and the Code of Practice.
It must be established that the person assumed to lack capacity agrees with the decision. I would like to see a more comprehensive explanation of the safeguards available before making further comment.	Draft Bill will be publicly consulted on. Comprehensive explanations will be included in the Code of Practice.
I have concerns about a Lasting Power of Attorney being able to be used to move people into care homes. There could be instances where a person is declared not to have capacity to make most decisions but they have strong views about not going into a care home, which should not be ignored.	Best interest principle is a primary factor in decision making taking into accounts a person's past and present wishes. Explicit in Legislation.
The proposals do not address the problem of an attorney being appointed who is outside the Island and therefore outside the jurisdiction of the Manx courts should there be any impropriety in the management of the donor's financial affairs. *(Michelle Norman -Attorney General's Chambers, Isle of Man)*	To be raised with Legislation Drafter.
There should be a mechanism for review and challenge as time and circumstances are relevant to the effectiveness of the safeguards e.g. suitability of the person may change over time.	To be raised with Legislation Drafter.
It could be beneficial to explore implementing a procedure whereby LPA's are subject to periodic check-ins (to be determined) by a governing/oversight body to fully ensure safeguarding of the donor.	To be raised with Legislation Drafter.

Within the 61 responses received, there were 98 identifiable elements related to the following themes:

1.	Independent Representatives is important	(19.38%)
1.a	Family input essential, who, what, when	(5.1%)
2	Effect of drugs, medical condition, disability effecting capacity.	(1.02%)
3	Communication - accessibility, support and training	(6.12%)
3a	Time limits/challenges require definitions	(11.22%)
4	Timing of intervention, capacity test, follow up, reviews	(10.2%)
5	Best interest, previous stated wishes, individual needs	(7.14%)
5.a	Risks /impacts	(8.16%)
6	Coercion, neglect, abuse	(16.32%)
7	Living Will integration.	(2.04%)
10a	Safeguarding	(10.2%)
10b	Access to records/storage and availability of LPA is a concern	(3.06%)

APPENDIX 7 Question 15

Table 15.2 Minimum Requirements for donee: If so, which of the proposed requirements do you agree with? Any other comments or do you have any further proposed requirements?

There were 79 responses to this part of the question.

Q 15 You told us:	We Will Do:
what happens if someone with capacity (Person A) clearly states they want a another person (Family Member) who may have been cautioned for an offence previously in the past e.g. 10 years ago - when Person A loses capacity is the wishes previously determined nil and void?	To be raised with Legislation Drafter.
How long has the donee been known to the individual and in what capacity. Apply something similar to the rules that anti money laundering regulations require, copy of photographic identity, proof of address, copies of last 3 months payslips (if applicable) when setting up Lasting Power of Attorney	The Department will consider this as a policy issue
Must remain resident on the Isle of Man. No convictions for any form for any violence, dishonesty or cruelty to animals. Should have an enhanced criminal record check. Must have visited the person at least annually.	Fully consider when developing the draft Capacity Bill and the Code of Practice.
I would also add Has not been previously convicted or cautioned against fraud *(Robert Juan Greggor)*	Legislation Drafter to be consulted - The list consulted on includes dishonesty and deception do the latter also cover fraud?
Everyone who applies to be a donee should have to write a statement stating why they are person who should be managing the need of the named person. this could be simply that the person is a parent or that the person has been their best friend since childhood. A record of the motivation could help if a case came forward that was not as it had first appeared.	DHSC to consider this as a policy principle.
Have some review process to ensure the Donee remains capable and is still alive	DHSC to consider this as a policy principle.
Another requirement which I feel should be applied is, a period for contestation should be applied, thereby if there is a possibility of minimising future disputes, it should be given every available chance for closure whilst the donor is still displaying capacity. The POA could be 'proposed' for a period of disclosure, 6 months potentially, until it becomes 'actual' POA...	Fully consider when developing the draft Capacity Bill and the Code of Practice.
it is always difficult to strike a balance between protection of potentially vulnerable people and over regulating and making processes prohibitively expensive and impractical. if some degree of proportionality could be considered then it may assist striking a fair and reasonable balance . An elderly lady going into residential care may not for example require PWC or KPMG to be the Donee if her only assets are a pension and bank account to pay for her care whereas a wealthy individual with diverse investment portfolios and specialist health requirements may require a greater degree of financial acumen. Perhaps these are matters the Advocate drafting the documentation should consider as well *(Jerry Carter- Carters Advocates)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Have some review process to ensure the donee remains capable and is still alive *(David Trace- Health Service Consultative Committee HSCC)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
We need to be ultra-cautious in how we view capacity - especially for vulnerable elderly persons in care - whether it be nursing, residential or sheltered accommodation. It has been brought to my attention where by - possibly too much freedom of decision making has been given to vulnerable persons - whereby they can arrange for private treatments for themselves at the area they are residing in - and pay for those services - even though they can obtain them free on the NHS. There does not seem to be any checking done to ensure that what they are paying out is fair, appropriate and proportionate to the treatment being received. Also - have they received enough advice from carers / wardens in the said area so they have the right information to make an informed choice - and can choose to pay fees rather than NHS treatment? And can they afford to pay such private fees? And is the institution, such as a Government run home insured in case of accident as a result of any private treatment? *(R W Henderson, MLC)*	DHSC to consider this as a policy principle.

Q 15 You told us:	We Will Do:
Add: 'Must be able to demonstrate an understanding of and respect for the person's wishes, opinions, beliefs and ability to make genuine best interests decisions i.e. decisions which the person would have made for themselves if they were able to. *(Catherine Sheppard – British Red Cross)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
what about need for a DBS ? maybe no one who holds a professional registration and against whom concerns have been raised?	Draft Legislator to consider
Is there going to be a regular review period to check that the donee remains with the above requirements and is capable of undertaking the role? e.g. in the place of an older couple where the spouse also deteriorates.	Draft Legislator to consider
LPA's undergo an interview to assess suitability. LPA's agree to undergo a review on a regular basis.	
Is Act going to monitor that donee is complaint with the requirements after they have been appointed? I think this could be checked on the regular basis, like DBS	Fully consider when developing the draft Capacity Bill and the Code of Practice.
How will you determine if somebody has been convicted or cautioned for terrorism etc.? who will provide the info? can or will another jurisdiction provide the info?	Fully consider when developing the draft Capacity Bill and the Code of Practice.
would not be disqualified from registration under the Regulation of Care Act 2013 s43 (1) and s44 (1) Has not been convicted under the Regulation of Care Act 2013, s152, ill treatment or neglect offence. Would a DBS check be carried out? This would identify if a person without convictions was barred from working with vulnerable adults *(Stephen Buttery)*	DHSC will review the requirements as to who can be appointed as a donee.
I would suggest that some of these exclusions should be tempered by some provisions or the rehabilitation of offenders act *(John Kermode)*	DHSC will review the requirements as to who can be appointed as a donee.
Had not been found guilty of breach of fiduciary duty Has a bank account in their own name with a history of at least 5 years or more to show they are not bankrupt in the UK also. Is not about to go to trial for anything fraudulent or unable at least to be considered until their is a welcome outcome to the trial. *(Bridget Carter)*	DHSC will review the requirements as to who can be appointed as a donee.
Presumably if an appointed donee does, subsequent to the LPA being in operation , fall outside the criteria due to offences etc, their donee status will be revoked and a further donee sought	Subject to determining the criteria that a donee must meet, based on the responses received, in the event that a donee no longer meets the requirements provided for in the Act.
this should be two persons rather than one to prevent vested interest. *(Fiona Smith)*	DHSC will review the requirements as to who can be appointed as a done and the number required.
Both my partner and I have a LPA which nominates each other as Attorney, we are Civil Partners. I do not think anyone should be unable to be an Attorney simply because of past/historical bad actions. We all make mistakes, If I want someone to act as my Attorney I do so knowing their past acts if they have any. There are dishonest Attorneys at Law, Police etc. so please do not make being an Appointed Attorney too difficult.	DHSC will review the requirements as to who can be appointed as a donee.
Will undertake the duty to act with the general knowledge, skill and experience that they possess. Will this depend on the individuals own "capacity"?	DHSC will review the requirements as to who can be appointed as a donee.
Has capacity themselves and is willing to undertake the role when they fully understand the responsibilities of it	
Will be an appropriate person sufficiently educated and trained to work alongside the subject of the act and ensure that their wishes are facilitated as far as reasonably practicable.	
I am pleased to see so many safe guards in place	
Convictions should potentially bar a person, however a caution for dishonesty could be someone who stole a Mars Bar when they were 18. There need to be a proportionality limit, or specific offences or thresholds set out. *(David Clegg- Legal Profession)*	DHSC will review the requirements as to who can be appointed as a donee.

Q 15 You told us:	We Will Do:
Regard needs to be given to the situation where someone becomes a donee and, a few years later, becomes say, bankrupt or convicted of fraud. Will this automatically revoke their donee status, or will that only be at the discretion of the doner, who may not necessarily be aware of the donee' s bankruptcy etc.? Also, a single parent, with teenagers under the age of 18, and who has concerns about their own chronic ill-health, may wish to make one of their children, a donee, as said child has been a carer for them for many years and has 'maturity beyond their years'. To disbar them on the basis of age seems unfair as the young person may have greater insight than others such as a distant relative who does not live locally but is over 18yrs old.	DHSC will review the requirements as to who can be appointed as a donee.
Must remain resident on the Isle of Man. No convictions for any form for any violence, dishonesty or cruelty to animals. Should have an enhanced criminal record check. Must have visited the person at least annually.	DHSC will review the requirements as to who can be appointed as a donee.
Someone who has not been cautioned for domestic abuse / violence/ coercive control.	DHSC will review the requirements as to who can be appointed as a donee.
The Donee should have full capacity	DHSC will review the requirements as to who can be appointed as a donee.
Consideration should be given for the mental health and other addictive needs of the donee. Someone with mental health issues or an addiction that is not managed should not be managing the welfare of someone else.	DHSC will review the requirements as to who can be appointed as a donee.
No convictions for any sort of violence, especially domestic violence Should be a limit on the number of appointments a donee can hold (so applications must have declarations of existing appointments) *(Jane O'Rourke)*	DHSC will review the requirements as to who can be appointed as a donee.
it may be prudent to consider if convicted of domestic violence against the individual. if they have, would they be in a position to step away from being husband/wife and make informed decisions?	DHSC will review the requirements as to who can be appointed as a donee.
The fact all these criteria may be net does not ensure the attorney will not act irresponsibly for reason of: *personal interest e.g. often children of the donor, often encouraged by their parent are more concerned to conserve assets than act in the interests of patient and on member of the family may favour of others. *capability does not necessarily convert to proper care for the affairs of the attorney. Rather like senior judges in England I prefer the accountability that comes from receivership rather than powers of attorney. See for example an article written in the Times by Jenni Russell 17 August 2017 and others which I am happy to provide and discuss. *(Tim Henwood- Legal Professional)*	DHSC will review the requirements as to who can be appointed as a donee.
I understand why the two exclusions for debt are included but would like to comment that this does not automatically mean that bankrupts or persons with debt relief orders will be tempted to steal or mismanage the assets of the person they care for.	DHSC will review the requirements as to who can be appointed as a donee.
Each person should be reviewed and approved individually, a 'one size fits all' doesn't apply in all cases. A hypothetical person who may have stolen a bottle of wine in their drunken 19th year, for example, should not be prevented from becoming a donee power or attorney in his 50/60's, I feel. To deny that hypothetical person, the chance to learn from his life choices is too restrictive in this type of instance. Don't forget how many times Donald Trump has been 'bankrupt'!!	DHSC will review the requirements as to who can be appointed as a donee.
perhaps some sort of oath or declaration or undertaking similar to an executors oath could be incorporated into the requirements *(Jerry Carter-Carters Advocates)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Although I agree with these requirements, there should be a time limit for these to be considered relevant, and some form of case by case judgement in some cases.	
In my situation I would not be able to becoming my sisters donee as debt grew on a jointly owned house. This was not ether of our faults and only happened due to two peoples I'll Health. I think you need to be careful when using the terminology used suggesting about people being in debt. This part would make our situation very difficult in deed and I needed EPA to sell our house to pay of the debt. Under this legislation I would not be able to do this	DHSC will review the requirements as to who can be appointed as a donee.

Q 15 You told us:	We Will Do:
I think if the person making the LPA is of sound mind and is not a vulnerable adult then their word should not be questioned, so if they choose a family member who has history than they will know this but have still chosen them that is their choice.	Fully consider when developing the draft Capacity Bill and the Code of Practice.
There is no direct reference in the choices to domestic violence and this is an essential requirement which must be taken into consideration. It might not have been treated as a serious offence but it is still a factor which should be investigated. *(Margaret Mansfield)*	DHSC will review the requirements as to who can be appointed as a donee.
I think they should be at least 21	
Something about not being able to personally gain from any decision made?	Fully consider when developing the draft Capacity Bill and the Code of Practice.
There must be clear record keeping of any such person being so designated. Rationale, validation, reasoning, evidence. That person must fully understand what it is being required of them and sign a declaration to that effect. There must be some way of monitoring such people and their actions. This must be done in the incapacitated persons interests and ensure their rights and assets are looked after in the best possible way - for them. *(R W Henderson, MLC)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
I agree with all the proposals above and suggest: - putting the positive requirement/s at the top of the list under 'Aged 18 or over' so that it serves to attract the right people by making clear what is needed and doesn't read as a list of what is not wanted though appreciate important to put unsuitable people off. - an amendment to the wording of both what is required sentences so they read instead: 'Will act with integrity, respect and uphold the person's rights and carry out the duty using the knowledge, skills and experience that may be reasonably expected from a person carrying out this function.' *(Catherine Sheppard - British Red Cross)*	DHSC will review the requirements as to who can be appointed as a donee.
They all seem reasonable however we are concerned about #4 and #5 as it is unclear who will assess this requirement. It would be more helpful to require that the donee understands the donor's wishes, and that they would be willing and able to articulate those wishes if the donor loses capacity. *(Upeka de Silva – Compassion in Dying)*	DHSC will review the requirements as to who can be appointed as a donee
What does any of e and f have to do with a loving relative acting for me? Perhaps some control is wise in the event of there being only one donee. *(D. Varley)*	DHSC will review the requirements as to who can be appointed as a donee.
Has not been convicted of drug use or importation/ sale of drugs	DHSC will review the requirements as to who can be appointed as a donee.
Can provide 2 character references from people of good standing in the community?	DHSC will review the requirements as to who can be appointed as a donee.
Police Check DBS (Maggie Harding)	DHSC will review the requirements as to who can be appointed as a donee.
1. This survey is inconsistent. Part F of the description says "convicted of". The tick box says "convicted or cautioned". 2. "Including aiding and abetting" is too broad. 3. I disagree with the specific inclusion of money laundering.	DHSC will review the requirements as to who can be appointed as a donee.
" Has not been previously convicted or cautioned for ill-treatment of patients under the Mental Health Act 1998"- I am uncertain what this is referring to. One is not usually "convicted or cautioned" under the MHA. It also refers to "patients" implying that it only applies to healthcare professionals. Could I have clarification please?? "Will undertake the duty to act with the general knowledge, skill and experience that may be reasonably expected from a person carrying out the same functions "-- This seems to be a sensible criterion. However, will this be interpreted to suggest that only trained or "qualified" people can act. Will this be interpreted in a way that will exclude family members for instance? *(Christopher Jagus)*	DHSC will review the requirements as to who can be appointed as a donee.
Is not currently a part of an open safeguarding investigation?	DHSC will review the requirements as to who can be appointed as a donee.
There is no direct reference in the choices to domestic violence and this is an essential requirement which must be taken into consideration. This violence might not have become a police matter or be regarded as serious but could have a harmful impact on the individual whose capability is being assessed.	DHSC will review the requirements as to who can be appointed as a donee.
The donee should be able to communicate effectively with the donor in their preferred language.	This will be facilitated

Q 15 You told us:	We Will Do:
Will a formal process be put in place for these checks such as or similar to DBS check. Presumably due diligence will be carried out in the usual way *(David S Gawne- Third Sector Official/Trustee)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
perhaps make the misuse of powers by donees a criminal offence?	The Department will
These proposed requirements presuppose that the power would only be given to a donee in the Isle of Man. Whilst this would often be the case, there are many individuals in the Island whose relatives live elsewhere. Whilst it may be impractical to prevent the appointment of a donee that does not live on the Island, consideration should be given to following the approach of the High Court in making receivership orders, namely that a person who is not resident on the Island will not be appointed as receiver except jointly with someone who is resident here. *(Michelle Norman- Attorney General's Chambers, Isle of Man)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
In the options above, there is no direct reference to domestic violence and this is an essential requirement which must be taken into consideration. This violence may not have become a Police matter or be regarded as serious but could have a harmful impact on the individual whose capability is being assessed.	DHSC will review the requirements as to who can be appointed as a donee.
How will the above be confirmed? Will need to be confirmed at the time of decision / reviewed - not permanent once in place.	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Being subject to Sexual Offences Act or Criminal Justice Act is too wide reaching for a definition. Needs to be clearer. *(Adult Generic Team)*	DHSC will review the requirements as to who can be appointed as a donee.
While recognising the vulnerabilities of those involved I would be wary of making blanket exclusions that may prevent people who have been 'rehabilitated' acting as Donee. Taking matters on a case-by-case basis would be my preference but I appreciate that this could be a lengthy and potentially fraught business. I don't think that there are easy answers here. *(Michael Manning – Graih)*	DHSC will review the requirements as to who can be appointed as a donee.
consider mature 16 year old carer of an incapacitated parent depending on the circumstances, consider restricted those who have been charged with domestic abuse to be excluded	DHSC will review the requirements as to who can be appointed as a donee.
I believe that donors whose mental capacity has been impacted temporarily or permanently are particularly vulnerable, and safeguarding is entirely critical to every aspect of their well-being. We need to be particularly vigilant with regard to convictions or cautions of the proposed requirements both in the Island, but also within other jurisdictions - how is it proposed that you will gather a complete and accurate profile of a donee and determine whether someone is 'fit and proper' based on requirements if they fall beyond Isle of Man jurisdiction?	Fully consider when developing the draft Capacity Bill and the Code of Practice.

Within the 79 responses received there were 143 identifiable elements related to the following themes:

1.	Independent Representatives is important	(15.38%)
1.a	Family input essential, who, what, when	(12.58%)
2	Effect of drugs, medical condition, disability effecting capacity.	(2.09%)
3	Communication - accessibility, support and training	(3.49%)
3a	Time limits/challenges require definitions	(11.18%)
4	Timing of intervention, capacity test, follow up, reviews	(6.29%)
5	Best interest, previous stated wishes, individual needs	(5.59%)
5.a	Risks /impacts	(18.1%)
6	Coercion, neglect, abuse	(18.88%)
10a	Safeguarding	(4.19%)
10b	Access to records/storage and availability of LPA is a concern	(2.09%)

APPENDIX 8 Question 18

Table 18.2 Open Comments on Key Characteristics of advanced decisions

Q 18 You told us:	DHSC Response
Is 16 years old an adult? There needs to be a common format, at present some AD's are ignored as they are interpreted as not applying to certain situations. *(Stephen Buttery)*	Ensure it is explicit in legislation
These must be on shared electronic documents so all involved in health and social care have access to decisions	Access to records- Integrated care record will assist with this. Although access has to be proportionate and relevant, Emergency or life-threatening situations may warrant the sharing of relevant information with the relevant emergency services without consent under Vital Interests remit.
Greater clarity is needed in who can witness /endorse these advance decisions and in how specific the stipulations need to be regarding treatments	Fully consider when developing the draft Capacity Bill and the Code of Practice.
The person themselves if they are able to have an opinion by any means possible their wishes should be obeyed, then their next of kin. *(Sonia Fargher)*	Code of Practice will assist and facilitate Next of Kin consultations.
about flipping time	
Only that it is important that an individual can withdraw or change their advanced decision, considering it could have been made in entirely different circumstances and that people change their mind for a variety of reasons.	Code of Practice will facilitate 'change of mind' provisions.
Will there be a standardised form for this?	Standardised remit in the Code of Practice
Will there be a review period when someone sets up the advanced decision? If it was set up at 18 years old perhaps they may forget about it and wish to change the circumstances.	A person can review an advanced decision, this will be facilitated within a Code of Practice
I feel strongly about a person making advanced decisions. A person who makes decisions around treatment or any care intervention should be honoured and respected. *(Ann Sharvi. – Sapphire Care Limited)*	The Department agrees.
Again the key element to this being implemented is that a nominated person is aware of the wishes of the individual. Having been in a situation where my father was asked if he wanted ECT - he was reluctant to say no - in case it upset the rest of the family. Once we all sat and had an open and frank discussion - luckily we were fortunate to do this - everyone understood the reasoning behind the decision and accepted it. So when he was at end of life stage everyone knew and accepted that no intervention would take place. It made a difficult time much more easier to deal with...being informed and aware is key	Code of Practice will assist in such circumstances and it is the Departments intentions to promote residents and families to have open discussions to assist implementation of Capacity Act.
Will there be a template for people to draw up advanced directives should they so wish, guidance on who / where such directives are stored & do they need any legal 'sign off'?	Standardised remit in the Code of Practice
I agree with this from what I understand of it having read the explainer document	
So, advance decisions can be made by someone over the age of 16yrs, yet LPA's etc. can only be made by someone over 18yrs? There needs to be consistency surely at what the minimum age is for all the matters this consultation deals with, and if not, explanations/ caveats that explain the differences from a legal perspective for the differences. Much of the reasoning for 18yrs being the threshold for entering 'adulthood' is anachronistic and needs to be updated to reflect modern day legal precedents. Under d) above, if the withdrawal of an advanced decision is not required to be in writing, how will it be recorded? Orally and witnessed? Needs to be clear. Similarly with e)	To be considered for the drafting of the relevant provisions of the Bill
If there is involvement of GPs in this process it must be adequately funded as it is not GMS work.	Department to consider Policy Principle
will the age being set at 16 cause difficulty as safeguarding adults guidance is set at 18?	To be considered for the drafting of the relevant provisions of the Bill
Care should be used with the wording around written and signed changes to advanced directives, a person may have capacity to change their mind but have become physically unable to write or sign their own name. *(Fiona Hall)*	Explicit in legislation and Code of Practice will facilitate Best interest process and procedures which will entail review/checks where possibly required.

Q 18 You told us:	DHSC Response
What about those who cannot make advances decisions? What will be done to safeguard them? I.e. those with learning disabilities	Best Interest principle is applied
I support all points, especially the minimum age and the choice to reverse all or part of a decision verbally at any time. *(Andrew Cole)*	
I have drawn up with help of my advocate is what I call a living will which gives instructions to the doctors and hospital when I go to end of life as my condition will not get better only worse	
The classic example of an advance decision is a will which with much certainty can be accepted to be acted on by the party making it. You say that courts currently recognize advance decision but there is no certainty that they will be acted on and the criteria to be applied to do so. In my practice I am reluctant to prepare living wills or DNA's exactly because although they may be one factor for consideration they are not followed in many cases. I agree that there should a concept of advance decisions but legislature must put rules around enforceability so that there is, to the extent possible certainty. *(Tim Henwood – Legal Professional)*	Explicit in legislation. Code of Practice
I am unsure that people would think far enough ahead to write down their wishes. It would however make it easier for sons, daughters etc knowing they did not have the responsibility of ensuring their relatives wishes were followed.	It is the Departments intentions to promote residents and families to have open discussions to assist implementation of Capacity Act
The person who has power should sign that they understand the advanced decision, will comply with it, unless they believe the decision is reasonably revoked by the person they are in charge of looking after the capacity of.	Fully consider when developing the draft Capacity Bill and the Code of Practice.
I was not aware that the court would use this as a guideline currently. This would have been extremely helpful to know as the impact of not knowing this has cost our family a lot of heart ache as well as financial losses. I think this would be very an important part of legislation	
Should this include "an appropriately qualified" person with definition? Otherwise, the receiver might be just about anyone…..where a relative wishes to be appointed, not providing a baseline means that the court is not obliged to ask whether a person has the general knowledge, ability etc to manage aspects of (for instance) financial affairs. This is where much abuse has arisen in the UK - the individual doesn't separate their own financial affairs from those of their charge either purposefully or not. The act probably needs a suitability test centred around the abilities etc. Support all points, especially the minimum age and the choice to reverse all or part of a decision verbally at any time. For consistency, the commentary above needs to be reflected here. The individual may change the decision but the POA or receiver must not be able to do so in their own right. *(David Trace - Health Service Consultative Committee HSCC)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Anything that can make an advance decision clearer is a good thing.	
I think there needs to be a provision whereby if a person's current actions contradict what they had previously included in an advance statement, the advance statement can be reviewed and modified to reflect the changed circumstances. This change would need to be recorded so accountability is built into the process. For example a woman who doesn't approve of her daughter's chosen lifestyle writes into her advance statement that if she loses the capacity to make her own decisions she doesn't want her daughter involved in her life and care. In later life she has Alzheimer's and her daughter visits her to take some clothes and toiletries and to find out if her mum is welcoming of her visit or not. The woman greets her daughter enthusiastically and is described by the care home as light and happy during the visit. The family decide that they will go against the woman's advance statement AND importantly if the woman indicates at any stage she is not welcoming of visits, the daughter will withdraw. *(Catherine Sheppard – British Red Cross)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
1. One of the challenges that the Mental Capacity Act in England and Wales has faced with regards to Advance Decisions is the lack of a standard form that may be completed by a person. As a result, health and care professionals are not able to easily recognise and therefore respect an Advance Decision which can cause significant distress to an individual wishing to plan ahead. *(Upeka de Silva ;Compassion in Dying)*	Standardised remit in the Code of Practice

Q 18 You told us:	DHSC Response
Very important that this is discussed with every person	It is the Departments intentions to promote residents and families to have open discussions to assist implementation of Capacity Act
(17 - Were the Courts to be required to consider the opinions of close relatives and friends as to the likely wishes of the subject then I would strongly agree rather than remain neutral.) I am strongly in agreement with the introduction of 'Advance Decisions' *(D. Varley)*	
it a great idea, everyone know what you want! and what is expected from them all changes should be in writing dated and signed by them and a wittiness at all times for the records *(Maggie Hardinge)*	
I Once told my GP that I wanted to make an Advanced Decision. He gleefully told me that they did not have the force of law on the Isle of Man, so I gave up. Six months later it struck me that I might be undergoing treatment at a UK when the need arose. So I made the advance decision anyway, and it is filed with my medical records. Isle of Man law MUST be as close as practical to English law to avoid confusion.	The IOM principles follow English legislation
How can you evidence alterations if they are not recorded anywhere? (Jo Dixon)	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Mechanism needs to be in place to review these advance decision so they do not remain in place and forgotten.	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Period of effect should be considered and a mechanism created for future challenge, especially when continuing to adhere to the advanced decision is liable to cause distress or harm, and the individual is indicating that they would seek to overturn the decision if they could. *(Dale Lowey)*	Fully consider when developing the draft Capacity Bill and the Code of Practice.
In principle these appear fine but advances in medical /scientific treatment should be taken in to account and this should be provided for. For example if a treatment is currently invasive or very expensive a person in 2020 might well refuse it but in 2030 might have a completely different attitude depending upon scientific advancements	Fully consider when developing the draft Capacity Bill and the Code of Practice.
Under common law, courts in the Island currently recognise advance decisions that have been made by a *competent* adult. It may be worthwhile clarifying what is understood by 'competent adult' vs an adult with 'capacity'. I don't understand the two terms to be used interchangeably.	To be considered in the drafting of the relevant provisions of the Bill

Within the 73 responses received there were 107 identifiable elements related to the following themes:

1.	Independent Representatives is important	(5.6%)
1.a	Family input essential, who, what, when	(7.47%)
2	Effect of drugs, medical condition, disability effecting capacity.	(1.86%)
3	Communication - accessibility, support and training	(18.69%)
3a	Time limits/challenges require definitions	(10.28%)
4	Timing of intervention, capacity test, follow up, reviews	(20.56%)
5	Best interest, previous stated wishes, individual needs	(14.01%)
5.a	Risks /impacts	(4.67%)
6	Coercion, neglect, abuse	(0.93%)
7	Living Will integration.	(5.6%)
10a	Safeguarding	(0.93%)
10b	Access to records/storage and availability of LPA is a concern	(9.34%)

APPENDIX 9 Question 19

Table 19.2 Advanced Decisions: Other decisions to be included in the list

If yes, what else should be considered?

There were 21 responses to this part of the question

Sample:

You told us:	We Will Do:
Would this cover children and adults with learning difficulties who may have become compromised and require medical intervention. Would a forced termination of pregnancy be part of this?	Termination not excluded
Decision to move off-island or allow children to move off-island.	To be considered in the drafting of the relevant provisions of the Bill
Participating in research	Covered under research
DNR needs to be mentioned specifically as something which can be included and of course we probably need to all have a debate on matters of euthanasia. *(Tim Henwood – Legal Professional)*	DNR is included in advanced decision principle
I don't think this is so black and white. I would like the opportunity to discuss this further if possible. I think there are many occasions where some of the above should be part of someone's safe guarding.	DHSC will review the requirements as to what additional safeguarding principles need to be incorporated into Capacity Bill.
By avoiding such issues they do not go away. *(D. Varley)*	
I'm not sure about including the facility and adoption decisions. I can foresee circumstances where it may be appropriate to make these decisions for the wellbeing and protection of the innocent baby/child.	Decision made on the needs of the child will fall under other legislation
Decision to gift large sum of money.	DHSC will review excluded decisions
decisions relating to gender transitioning for those under the age of 18 years.	DHSC will review excluded decisions
j. any other type of physical intervention (other than essential medical intervention) which nonetheless would normally require an individual's consent; I believe that non-consensual sterilisation (hysterectomies, vasectomies etc.) falls within this category of physical intervention?	DHSC will review excluded decisions

Within the 21 responses received -
There were 21 identifiable elements related to the following themes:

1.a	Family input essential, who, what, when	(4.54%)
2	Effect of drugs, medical condition, disability effecting capacity.	(4.54%)
3	Communication - accessibility, support and training	(9.09%)
3a	Time limits/challenges require definitions	(13.63%)
5	Best interest, previous stated wishes, individual needs	(22.72%)
5.a	Risks /impacts	(13.63%)
6	Coercion, neglect, abuse	(9.09%)
10a	Safeguarding	(22.72%)

APPENDIX 10 Question 23

Table 23.1 Additional Comments: Age Requirements regarding deprivation of liberty

Additional comments:

There were 21 responses to this part of the question.

The Depravation of Liberty principle will be addressed in Phase 2 of Capacity Bill, therefor the comments are noted in this consultation, but actions will be pending a further consultation with public in 2021/22

Sample:

Q23 – Additional Comments You told us:
if a person can vote at 16 on the IoM then they should be afforded the same rights as a person who is over 18. This is a separate piece of legislation which needs to be reviewed. *(Fiona Smith)*
People are deprived of their liberty far too quickly and in many cases for the convenience of others.
Will this apply to those in HMP Jurby? Also those on bail and under the care of a social worker or probation officer?
My earlier comments about age refer. If 18yrs is deemed to be adulthood, then it should be consistently applied in these matters in this consultation. The reality is that there are many 16yrs olds who act and conduct themselves far better than 18yrs olds and vice versa. While there needs to be a 'threshold age' doing so purely on chronological age is going to continue the current situation of many mature teenagers being unable to legally help/assist. However, the converse also applies in that will 16/18yrs olds always understand that some of their actions could be deemed as depriving someone of their liberty, and as such they could be prosecuted?
It should apply to all ages. You should also look at the needs of the carer - have they received any support or training , are they aware of what they are doing is wrong, has the individual decided this is how they want to be cared for? Poor choices are sometimes based on lack of knowledge or misinterpretation of information, poor training.
To assume a person under the age of 18 does not understand and have understanding and capacity to make informed decisions in their particular instance is quite insulting. Those situations should be addressed on an individual basis and to blanket all under 18's as not able to make those decisions, I feel would be wrong.
i am not sure which age would be appropriate ; further consultation with education and child care experts would probably give a better informed opinion than I could *(Jerry Carter- Carters Advocates)*
Supported living situations should be on a case by case scenario, and not automatically invoked.
Logically in line with other decisions at 16+ e.g. marriage, voting *(Andrew Cole)*
22. As DoLS is due to come to an end in England and Wales and is likely to be replaced as you'll know by the Liberty Protection Safeguards, it doesn't seem wise to use the term Deprivation of Liberty as it will mean this new bill/act is outdated very quickly which would be a shame after all your hard work! 23. 16 years and above *(Catherine Sheppard- British Red Cross)*
Any age if required and proven
The obvious answer is not 'Neutral' but 'strongly agree however how has someone become deprived of their liberty (other than 'Sectioning') if in such a condition? *(D. Varley)*
I think it would be easier to comment on this with more information about how it ties in with existing Child protection legislation. *(Christopher Jagus)*
If you can vote, marry, join the army and pay tax at 16, then the law should apply to you at 16. I strongly believe that the legislation should at least match that of the UK and if possible provide additional safeguards not less. In order to do this it is imperative that the legislation kicks in at 16 not 18.

APPENDIX 11 Question 25:

Table 25.1 Other Comments (with permission to publish)

Q25 Additional Comments You told us: These are all publishable comments
DoL safeguards need be robust and person centred. They must allow for independent assessments and scrutiny of all documentation, including care plans, Deprivation of Liberty plans and Restriction of Liberty plans. We must not forget that no matter what we call deprivation of liberty it still has to be completely justified. As Lady Hale stated in the Supreme Court 'A gilded cage is still a cage' *(Stephen Buttery)*
Something needs adding if circumstances change
Please take into consideration the fact that some vulnerable people may be subject to undue influence or being under or over medicated and that more than one opinion should be sought by independent means. No one person should ever have the power to presume a person is either of sound mind or not of sound mind and no one should be presumed a trusted carer until all checks have been made! For example there should always be a "letter to act on behalf of," signed and authority to act on behalf of entered into all systems and any changes made in writing accordingly! Any agreements rescinded should always be in writing and entered on all systems before any changes to whoever already had consent are even considered. *(Bridget Carter)*
Looks thorough and wide ranging enough if implemented There needs to be further guidance/templates available for creation of and witnessing/ratification of advance decision documents
The isle of man legislation with regard mental health receivership is nor fit fur purposes and should be also considered in legislation as the currents receivers interpret their somewhat different from what it appropriate and neglect their duties to obtain their clients wishes. *(Sonia Fargher)*
The explanation of the direction of this proposed policy so far seems eminently sensible, and once developed and passed into legislation will provide significant safeguards and clarity over a range of issues which currently create some confusion for those working with people facing difficulties due to their mental capacity. This said it is vitally important that when this and all other government policies that involve people with any type of disability that important information about them is available to them in a format that they understand , our particular interest is concerned with those living with the additional challenges of sight loss and that any decisions about blind or visually impaired or deaf blind people are made only after those making assessments, judgements or recommendations about their capacity can evidence or be sure that any individuals concerned have been communicated with in their preferred style of communication
The Capacity Policy sound exactly what is needed on the IOM. In my experience relating to people with dementia their freedoms in many instances are removed far too quickly and easily. This needs to be stopped.
Having agreed with the IOM working title I am now wondering if it should be more specific? People with trauma injuries through RTC or accidental toxicity or some sort of acute episode that has rendered their mental capacity to such a stage that clinicians will have to make a life changing decision for them. It is not really a mental health issue but a result of an external debilitating event.
Consider an independent board to review the Capacity policy which includes politicians, health care professionals, third party sector representatives but also carers. This would help get an overall view from every service / individual involved in daily capacity decisions.
Clear & concise guidance should be provided when enacted for a variety of settings & also in simple language for the general public. It is imperative that a review & check system be included for when donors and / or capacity changes or fluctuates. Clarity on how legally binding advanced decisions would be, particularly in relation to health care and end of life decisions or would they just be 'considerations' with final decisions left up to 'professionals'?
I was in care as a child and felt that my wishes were never taken into account which led me into placements where I was abused. I would like to see some sort of check and independent person able to see that things are as they seem - I am not sure if this is in here I could not see it
The Department should require a Court Order to do anything which a private citizen would also require a court order for, anything else is creating a system with a lack of accountability. *(David Clegg – Legal Professional)*
Mental Health / Mental Capacity has been arguably been sufficiently researched/ debated and implemented by other jurisdictions comprehensively enough for the IOM to take legislation from say Scotland, and import it more or less wholesale, albeit with minor alterations/ local contextualization. In not doing so, and creating its own 'niche' provisions, adds additional bureaucracy and creates issues such as increased difficulty in getting clinicians/carers to come to work (or do locums) on the Island who are accustomed to more modern legislation and approaches. It may also present additional issues in getting appropriate legal representation for those who come before MHRTs - an issue that already exists with the current provisions.
About time
A comprehensive and on-going training/education/awareness programme will need to be established to ensure that both public and professionals are aware of, and adhere to, this new Act. Consideration will be needed regarding the recruitment of staff for new roles such as Independent Capacity Representative. Which Court will have jurisdiction in these matters? In the UK there is The Court of Protection. Thank you for the opportunity to comment.
It's nice that the government are thinking about capacity advocates, but finding people who are knowledgeable and trained/skilled in this area will be a challenge. Would hate for such vulnerable people to be let down through lack of knowledge, skills and training,

Q25 Additional Comments You told us: These are all publishable comments
I think everyone should be allowed to die pain free and with dignity ,and that we should look at assisted deaths to enable people to do this
I hope this can be put in place quickly and help some of our future vulnerable people.
Looking forward to seeing the next stage a how it develops.
Think about a living will
This is a good initiative. The provisions of Chapter 7 of the Mental Health Act and the Powers of Attorney Act 1987 create an unfortunate duality in the law and this is an opportunity to treat matters as one. Although myself not from an English background, I will still like to see a court of protection I would still like to see a separate court of protection Finally judicial comity and recognition of international measures and similar instruments from foreign jurisdictions should be included so that people lacking capacity from foreign jurisdictions are not put to unnecessary additional burden *(Tim Henwood – Legal Professional)*
There is a lack of facilities on the island for the care of mentally ill people who are violent or who behave aggressively. My brother is currently in a care home suffering from a form of dementia caused by alcohol and a stroke. He is extremely aggressive and suffers paranoia which includes a dislike of old people. A care home is not the right place for him. There is still a need for a permanent residential psychiatric ward for cases like his. Mannanan Court is excellent but does not take long term patients. The policy should include a clause about appropriate residential care for those people who lack capacity.
Put it in place as soon as possible *(Patricia Watts)*
We should have assisted/accompanied suicide to those who suffer from terminal illness and/or severe physical and/or mental illnesses, supported by qualified doctors. Similar to Dignitas. *(Mathew Birks)*
I feel it is very important that the current form of EPA should be extended to include the decisions about health and welfare. If someone already has an EPA set up (like myself) what will happen if the new legislation comes into force? Will a completely new LPA have to be made or will it be possible to just add to the original EPA? *(Sandra Holland)*
the role of Independent Capacity Representation in my opinion should be managed by the Attorney Generals Chambers as they have both resources and experience and can effectively interface with other involved agencies Overall I welcome the Bill and the consultation process. with the caveat that simple enduring POAs are not hampered by any increase in cost or regulation the Bill is clearly addressing the very real issue of protection of potentially vulnerable people in a number of ways I would as a practising Advocate urge that there would be some training for legal practitioners who are at the "coal face" and would in the majority of cases be the party assessing the needs and requirements of the Donor and the risk factors I hope this rambling response is of assistance *(Jerry Carter – Carters Advocates)*
I am very glad to see that this is being considered. There is not enough currently in place to protect and support people in this position. And their families. I would also like to suggest that people with lifelong conditions such as bipolar, are never signed off, and are offered at least quarterly appointments when stable so that they are always 'in the system' and don't have to start at the beginning each relapse. I believe this would reduce the relapses and although I can see it may appear recourse heavy, has the potential to reduce the need for police/court/ambulance/hospital/prison services and protect the person from destroying their business/reputation/belongings/relationships/family/savings in future.
We need to ensure any matters pertaining to a person or persons family that fall under this new law is dealt with in a timely fashion. I believe it is just as important to deal with these matters swiftly as a matter of law as the law itself. I feel guidelines for this should be drawn in to the new legislation. This is to protect years of people's lives being wasted, brushes aside and to stop the cause of further mental health issues. Currently the support is just not there for family's who are living in this situation daily. Lives and families are torn apart and just because there are not clear timelines for things to be done or for people to be accountable for not doing their jobs
Cannot see any notion that there will be a parallel to the office of the public guardian here. That is a really important protection, as POAs operating when someone has lost capacity must be able to account for their actions. None of the principles set here go beyond the courts being able to appoint someone. Is there an existing facility in the IOM to cover that? *(David Trace - Health Service Consultative Committee HSCC)*
I feel in my case as a carer more information/advice should be given re the necessity of power of attorney etc. Following diagnoses of my husband's Dementia four and a half years ago it took lots of phone calls and pestering to get a day placement for him at cummal mooar for 5hours which he was adamant he did not want. I am grateful for the care he now receives at Crovan Court (fluids only). During lockdown he was extremely well cared for at Reayrt Skal. I know this comment is not entirely relevant to the Consultation but our whole Health/Wellbeing needs sorting/reviewing. I myself was diagnosed with stage 4 breast/lung cancer in January and am receiving excellent day care at Nobles Oncology unit. I do not have a social worker. I am lucky to have a daughter on the Island who could not do more for me and a son in Germany who was visiting every 6 weeks prior covid.
This is long overdue and I hope it's not just a paper exercise...the Island needs a specific policy NOW.
Yes. As a mental health nurse and qualified Best Interests Assessor (in England and Wales) I feel it is important that on the Isle of Man mental health nurses should (just as in England and Wales) be able to carry out DoLS assessments (subject to suitable training in the Manx DoLS regulations).

Q25 Additional Comments You told us: These are all publishable comments
I feel family members are often more concerned with the cost of care than the well-being of the person. Final decisions about what and where is best for a person lacking capacity should be made by a professional medical and social work team who have the persons best interests in mind and not personal financial loss.
I fully support the concept as outlined on this page for ongoing research, appropriate body to be used. If this legislation is introduced it needs an evaluation date set to assess its effectiveness, appropriateness and that individuals who have been effected by it have their cases reviewed from time to time to see that all relevant policies, procedures etc. have been followed and that any decisions that have been made on behalf of an incapacitated person are the correct ones, and in their best interests taken from a holistic assessment of their life needs and what is best for them in all circumstances. *(R W Henderson, MLC)*
Thanks for giving people the opportunity to contribute to this consultation. Some of the text includes reference to 'the vulnerable'. 'particularly vulnerable people' etc. Is it possible to avoid the use of the term 'the vulnerable' and to talk about people who are at risk rather than using 'vulnerable people'? Several reasons including: 1. Consultation several years ago of people using services when the No Secrets guidance was reviewed resulted in a large number of people rejecting the term 'vulnerable', 'vulnerable adult' and more recent legislation across the UK and British Isles has moved away from a focus on vulnerability which many people using services said they found stigmatizing and felt like it put the blame and focus on the person's individual characteristics rather than the risk factors they were facing in their lives so things then shifted from vulnerable adult to adults at risk and adults who are at risk. It would be really good to see that shift in direction reflected in this new policy. 2. Many people we support are at risk of abuse or harm because of their circumstances and situation rather than their personal vulnerability so for example we may be supporting a refugee who is his country of origin was a high earning professional person and not a vulnerable person but now a couple of years on this same person is at risk because they have lost their home, income and family. The focus of a capacity policy should be on maximising people's capacity in the first instance and supporting people to make their own informed decisions and then where people lack capacity to make one or more of their own decisions on making best interests decisions rather than on 'vulnerability'. Appreciate all the hard work you are putting into this consultation and look forward to finding out more about the bill and the policy as it progresses. Kind Regards *Cate (Catherine Sheppard – British Red Cross)*
Compassion in Dying would be pleased to support you in taking this work forward by sharing the lessons we have learned from helping over 56,000 people to understand and benefit from the Mental Capacity Act 2005 in relation to end-of-life care. If you would like to learn more about open sourcing our Advance Decision pack, please do get in touch. Wishing you all the best! *(Upeka de Silva - Compassion in Dying)*
Further to 24 'Neutral'. When the power is dependent on some defined loss of competency then some independent arbiter may be a way of the Court divesting itself of a functional responsibility (or at least a layer of it). When the POA is without such a limitation the relevance of such an arbiter seems only valid if there is some question of the donors competence at the time it is signed. *(D. Varley)*
It should include a provision that makes it an offence for the appointed person to sell property / use funds for any other purpose than to the benefit of the incapacitated person. I personally know of families that with the aid of a power of attorney have used funds for cars/ holidays / home improvements etc. Whilst the person they should be looking to is left without proper care/ heating/ new clothing etc.
One law doesn't fit all, in these situation, a lot more works need to be completed, training for the staff on the ground. *(Maggie Hardinge)*
My understanding of the English Mental Capacity Act 2005 is that it was intended to provide a definition of capacity, and a framework for other legislation. A Manx equivalent is long overdue, so please do not get hung up on detail and delay the Act. Get the basics done, and soon.
The proposed Capacity Bill appears well researched and well considered.
thank you, this is a much needed addition on the island and will help a lot of our vulnerable members
In terms of new legislation, I would like to reiterate that I have been involved with Capacity Legislation Working groups and committees for probably ten years now, with (frustratingly) little to no progress made in terms of legislation. I welcome the fact that there now seems to be a will to progress much needed legislation. I assume that there are still large amounts of records and information existing from previous work done in this area that can be drawn on to help to formulate the new framework? At the present time, we are left with many legislative gaps due to the lack of legislation, and a lack of clarity about how practitioners should act in caring for others who lack capacity, when it comes to areas such as deprivation of liberty. In addition, I think careful consideration needs to be made regarding the interface with existing Mental Health Act legislation. At the current time, for instance, patients with dementia, who end up needing to be admitted to hospital, end up detained under Sec 3 of the MHA purely because they are unable to consent, and because of concerns about deprivation of liberty in view of case law such as the Cheshire West judgment. In addition, this is an issue for the Department, as these patients are then subject to Sec 115 aftercare legislation under the MHA placing a responsibility on the DHSC to provide aftercare, which includes funding nursing/residential home placement, irrespective of the person's financial means. There are increasing numbers of these, and this results in the DHSC spending many hundreds of thousands of pounds each year to place people in appropriate care settings. Carefully drafted Capacity Legislation must interface seamlessly with Mental Health Legislation (or even potentially be part of the same piece of work, as in Northern Ireland), so that these areas can be appropriately managed, and better use of the MHA can occur. *(Christopher Jagus)*
It is our experience from having a disabled child that professionals (teachers, doctors, social workers, etc.) come and go, and never get to know the person in the same way as family members. Family (parents & siblings) are the only constant in their lives.

Q25 Additional Comments You told us: These are all publishable comments
All communication must be in the preferred language or medium of the person being assessed for capacity. e.g. Sign language, Braille. English, both written and spoken, is not always the first language. The policy and subsequent legislation must ensure that this is not a default and that a suitable translation/interpretation is provided. When D/deaf individuals are being assessed for capacity, their communication needs must be addressed through the provision of a Sign Language Interpreter, Lip speaker, and note taker or by clear, face to face communication as appropriate.
All people should be offered the possibility of speaking with the Independent Capacity Representative but doctors should not be required to consult the Independent Capacity Representative, and await their decision, if the patient does not want to do so because this could delay/affect the medical treatment required.
In order to protect vulnerable people, and with the increasing older population, the Mental Capacity and Deprivation of Liberty legislation should be proceeded with without delay *(David S Gawne - Third Sector Official/Trustee)*
In regard to point 17 'Court can appoint someone to act on behalf of someone who has lost capacity regarding health and welfare' - I would like to expand on why I strongly disagree with this point. In the case of adults with a learning disability, there is an established culture of ownership around decision making based on an assumption that the individual does not have capacity and that others involved in their life 'know what is best for them.' There are already examples of inappropriate use/misinterpretation of legal processes in decision making in respect of adults with a learning disability and lack of understanding and commitment to the best interest process. I strongly believe that there is a danger of undermining this process further and negatively impacting on the rights and quality of life of adults with a learning disability.
Q.17 There would have to be strong safeguards and mechanism for challenging if the person appointed wasn't appropriate. *(Jo Dixon)*
Q17. Did not have an option to comment, and is one of the most contentious points. There is no specification that this would only apply to those who could and probably would have made an LPA had they gotten round to it, there is no indication that it would only be pursued when processes had failed, and there is no indication that it would be limited in terms of scope or period of effect. Such a proposal will no doubt appeal to certain groups, but it would potentially undermine the core principles of the proposed bill. This would be a reversal of current notion that no person has rights to make a decision on behalf of another person, and weakens the requirement that decisions must be taken in their best interests. Depending on application this could be a significant step back from the current common law position. Q22. In principle applying to other areas is a good idea. However, the definitions used are not consistent across government, third sector, or even other legislation which would prove problematic. It needs to be clear what constitutes each type of service and what does not. *(Dale Lowey)*
I would like to expand upon my response to No.17 in respect of the court appointing someone to act on the behalf of someone who has lost capacity. This has the potential to significantly impact upon adults with a learning disability. There is real potential here for the best interest process to be undermined, particularly by individuals who believe that adults with a learning disability do not have capacity to make any decisions or choices and who believe they 'know what is best.' Adults with a learning disability have fought long and hard to have their rights and opinions recognised and there is a danger that individuals will have their quality of life significantly impacted by an individual being appointed to make decisions on their behalf.
We agree in principle and the allocation of strong advocates for this client group. it will not be efficient to have convoluted paperwork processes, but clear and efficient guidance. The guiding principles a and b should be one, keeping in line with UK as SW's are used to working with this. Training is essential as some professionals continue to struggle with the assessment of capacity. Best interest assessors' needs to be incorporated into this. Some of the safeguards put in place are too wide reaching and could exclude individuals who may be deemed suitable and appropriate to act as LPA. *(Adult Generic Team)*
Graih serves those who are homeless and in insecure accommodation and as such we frequently come across very vulnerable individuals, often with chronic mental and physical health problems, whose capacity fluctuates widely. We recognise that this is a difficult and key area and while we very much welcome this consultation and proposals we would urge the Department to consider those who regularly fall 'outside the box' when developing this legislation. This particularly applies to those who have little or no support network or family. *(Michael Manning – Graih)*
Once the bill is issued the opportunity to provide further input would be welcome
1. Whilst the current system on the Isle of Man does have room for substantial improvement, we do not think that bringing in English style legislation that introduces Lasting Powers of Attorney is the best way of making those improvements. 2. One area of the current Manx legislation that does require improvement is the provision for appointing an Attorney to make health and care decisions. Currently, this is done with an advance decision/living will. Whilst useful, they are also often inadequate, and do not allow for the same legally enforceable and broad decision making power as the English LPA does. Introducing something similar to a Lasting Power of Attorney for health and care decisions would therefore be a worthy, and in many ways necessary, improvement on our current situation, as it provides a legally enforceable document for this purpose. 3. Looking at the forms in England, there are two Lasting Power of Attorney forms – one for health and care decisions and one for financial decisions. Introducing a similar split here would be a sensible part of bringing in the above changes. 4. Similarly the proposed safeguards relating to who can be an Attorney are a sensible improvement. Ensuring that those who have committed serious crimes, or who are bankrupt cannot be appointed as Attorneys is the right approach, as is including a provision to stop the appointment of such a person should they become bankrupt or are convicted of a serious offence after being listed as an Attorney. 5. A number of other tweaks for clarity's sake, such as introducing a capacity policy and a code of practice would help Advocates, care workers and members of the public understand how Powers of Attorney work and how to make them. They would also assist in safeguarding those who make a Power of Attorney.

6. However, much of what is proposed in the consultation's explainer document is already covered in Manx law, and is not a necessary justification for bringing in new legislation. Indeed, many of the points noted are actually in Part A of our current EPA. Even where there may be some use in clarifying current arrangements, for example around mental capacity policies and assessments, these assessments are already a part of the current legislation and clarifying them does not need a whole new piece of legislation. Much of it could be achieved by clarifying and streamlining Part A of the current EPA.
7. Furthermore, the larger sensible and beneficial changes mentioned above could easily be brought in with amendments to the current legislation. Bringing in a wholesale change to bring us in line with the English legislation therefore appears to be totally unnecessary and brings with it a number of issues and questions.
8. One issue relates to the complexity of the forms. The current EPA form on the Isle of Man is 7 pages long. The LPA forms in England are both 24 pages long. They are in depth and complex, and include a lot of information. This appears to be largely a result of trying to include in the document much of the information a person would need to know to fill out the form without legal assistance. Not only does this bloat the form substantially, but it would likely be information overload for many, particularly those who have never encountered the form or this area of law before. It strikes us as a better option to improve Part A of the EPA to include much of this information, and advise those who intend to fill one out to speak to an Advocate ahead of doing so, rather than trying to provide them with all the information to do it all properly themselves. This could lead to questions of capacity in the future – if someone with deteriorating capacity managed to fill out an LPA without legal assistance, could it be argued that they did not fully understand?
9. Instead of introducing a whole new piece of legislation and bringing in a whole new form in the LPA, why not amend the legislation to split the current EPAs? We could have an EPA for financial decisions and an EPA for health and care decisions. This would reflect the English position and fill the gap in our current legislation in relation to health care decisions, without the need for new legislations, or new complex forms.
10. Again, we could bring in the new items in relation to suitable/unsuitable Attorneys as an amendment to the current legislation. There is no need for whole new legislation for this purpose either.
11. The new legislation would likely need an expanded and improved legal infrastructure to support it. In England there is an Office of the Public Guardian and a separate Court of Protection. What provisions is the IOM Government proposing to make to deal with this increased infrastructure need? Will they be introducing something similar to the Court of Protection and Public Guardian? How will the current Manx Courts cope with the increased complexity and workload? This would be expensive, or would slow the current courts down.
12. Overall this just feels like reinventing the wheel. Why bring in such substantial and unnecessary changes when some moderate amendments to the current Manx law would allow us to keep our current, and in many ways simpler, system?
13. In summary:
a. Bringing in a power of attorney form to deal with health and care decisions would be useful
b. Putting limits on who can act as an Attorney would also be a sensible improvement
c. New policies clarifying parts of the process would make it easier for all to follow and understand
d. Many of the comments and proposals are already covered in Manx law
e. The useful changes could all be made with amendments to existing legislation, and bringing in an equivalent to the current UK system seems complex and unnecessary
f. Changing Part A of the EPA and splitting it into two forms – one for financial decisions and one for health and care wishes would achieve most of what is needed

* I would propose 'Supported Capacity Representative' over 'Independent Capacity Representative' since the role is ultimately one of Supported Decision-Making.
* I am curious as to whether legislation in jurisdictions beyond the shores of the UK have been explored. I think there may be value in doing so, although I appreciate time and resource constraints.
* I quote the following from Page 3, "Capacity issues could potentially affect everyone. A person's capacity to make decisions may be impaired for a variety of reasons, such as having significant learning difficulties, learning disabilities, mental health problems, suffering a stroke or head injury, or the onset of dementia."
Within the category of "learning difficulties and/or learning disabilities" is the possibility (likelihood?) that capacity has been impaired since birth. For example, for a person with an intellectual or developmental disability (IDD), it is understood that capacity has not suddenly been lost, as might be the case for someone experiencing a stroke, head injury, or onset dementia, who has in fact 'lost' capacity whether temporarily or more permanently.
I find that this proposed legislation speaks to those who have experienced the loss of capacity, rather than to those who are born with impaired capacity. I think it's important to realise the distinction when we consider decisions such as appointing a Lasting Power of Attorney. In my opinion, Supported Decision-Making for people living with IDD requires a different and thoughtful approach worthy of visiting here.
* Finally, I realise that 'Research' is not within the current public consultation, but as the parent of a individual with high support needs, I cannot conceal my concern when I read, 'the Department is proposing to make provision as to research that is carried out on, or in relation to, a person who lacks capacity.' I am not entirely certain what this means - I think clarification is necessary. Despite the 'guarantee' that, 'The Bill will require such research to be approved by an appropriate body and carried out in accordance with strict conditions based on long-standing international standards', I urge you to seek public consultation. This is critical in maintaining transparency pertaining to the rights of our most highly vulnerable citizens.
Thank you for the opportunity to review this document, and be part of this consultation. I see many positives here, but would really like to see the voice of those living with IDD (and impaired capacity) better represented here. Kind regards!

APPENDIX 12 Other comments provided by organisations during the consultation process

1. You said
'It is a general principle that any person allocated a public sector rental property is capable of independent living and therefore the proposed Bill has limited consequence for affordable housing. The Department does however support all of the policy principles in the consultation and notes the reasoning behind them.
2. You said
'We wish to highlight is the need for Best Interest Advocates'
3. You said
1. Mental health: the overlap between capacity and mental health is critically important for us. We have failed to prosecute (or failed to prosecute successfully) in some cases where the lack of capacity legislation meant that the actions of a mentally ill person should have attracted sanction from a court, but did not do so. The presumption of capacity would help, especially in cases such as those where a patient in a mental health facility assaults a carer.
2. Elderly people: we are increasingly seeing cases where elderly people are being exploited, either by strangers (usually via the internet) or by those close to them, such as carers or people who somehow inveigle their way into a trusted position. Protecting such people and making sure that there are measures readily available to stop them from being exploited would be really useful.
3. Following on from 2, it would be welcomed if the legislation afforded proper protection to those people, who are vulnerable, not just because of age. However, the suggestion that there should be an independent advocate for those perceived to be in need is especially important.
4. Operational police officers often become embroiled in cases where eccentricity or odd behaviour is thought to require mental health intervention. It is therefore important that the suggested definition of capacity is set out in the legislation. This would provide much needed clarity, which would aid operational decision making.
5. Care will need to be taken to ensure that those people who assume responsibility for those without capacity are fit and proper. Saying this and creating an appropriate framework and supporting regime are harder.
4. You said
1. Decisions on capacity, and consequent potential for deprivation of liberty, require high level of scrutiny and effective and accessible legal safeguards. No one should be treated as unable to make or act on a decision unless all practical steps have been taken to assist him/her, without success. Consideration should be given to requiring a formal assessment of the adult's capacity, and also to the qualifications, skills, and experience required for a person to be empowered under the legislation to assert incapacity. For example, in Scotland the starting point is a presumption of capacity and this can only be overturned where there is medical evidence stating otherwise. Consideration should be given to a legal right to challenge assertion of incapacity, with the burden of proof laid on the person asserting incapacity, and access to legal aid for persons of moderate income.
1. Any decision taken should aim to preserve the person's freedom and independence as much as possible
2. Age Concern Isle of Man strongly believes that the wishes of a person lacking capacity must be a prime consideration in any decisions about their care. The principle of "no decision about me without me" must be fundamental to the legislation, and to the implementation in practice. Resources should be made available to assist individuals to have fullest input possible into decisions affecting them, particularly in relation to care planning and health care.
3. Consideration should be given to the best method of addressing potential conflicts of interest, either through regulation, or within a Code of Conduct with the power of statute. Individuals who fund their own care should be given particular consideration to ensure adequate safeguards are in place to prevent conflicts of interest by persons making decisions about their care or about deprivation of their liberty. The Adults with Incapacity legislation in Scotland provides that a continuing power of attorney or a welfare power of attorney must incorporate a certificate by a practising solicitor or a doctor that the solicitor or doctor has interviewed the granter immediately before he or she signed the documents; that the solicitor or doctor is satisfied from their own knowledge or having consulted other named persons that the granter understands the nature and extent of the power of attorney; and that the solicitor or doctor has no reason to believe that the grantor is acting under undue influence or that any other factor vitiates the granting of the document. It would be useful for an evaluation to be made of the benefits of applying a similar arrangement on the Isle of Man
4. It is very important that the donor has appropriate information to help them make decisions about who would be the best person to take decisions on their behalf should they become incapacitated. The Code of Conduct will play a critical role in determining the duty of care of the donee, and setting the standards which must be met in the performance of their role. The Office of the Public Guardian in the UK plays a critical role in investigating any concerns about the actions of donees, and has key safeguarding duties. It is difficult to comment on the proposals above relating to criminal records without information as to how any DBS checks would be administered, when and by whom the initial procedure would be carried out, how regularly it would be updated, and what would be expected of the individual donor.

5. The Bill is a very important piece of legislation, which will have a profound impact on the lives of some very vulnerable people, and as such must be subject to an appropriate level of scrutiny to ensure the best possible outcomes for vulnerable individuals.

Easy reader versions of the Bill and associated papers should be made available so that the people most likely to be directly affected by the legislation can make their views heard.

All the protections provided by the Office of the Public Guardian in the UK should be available to vulnerable people on the Isle of Man. There should be careful consideration as to how this can best be effected on the Island

It is essential that adequately funded legal aid is available so that a person of moderate means, either a donor, someone authorised to act on his or her behalf under the Act, or anyone claiming or having an interest in the adult's welfare or affairs, is able to access legal advice and the protection of the law.

Protected resources should be made available for the implementation of the Bill.

5. You said

1. (Q9) The test must state" the person must be assumed to have capacity unless proven otherwise" " Comprehend" should be stronger e.g. "fully understand"
   Their ability to reach a decision " must not be influenced by any abnormality of their mental state (e.g. content of any delusions or hallucinations)
2. (Q10) There needs to be a distinction drawn between "Treatments" for any potentially life threatening illness and palliative "life sustaining" interventions such as pain relief and not allowing dehydration etc. These will always be required and in the patients best interest whatever advanced decision they may have Made.
3. (Q11) The beliefs and behaviours of the individual when previously well and known to have capacity should weigh more heavily than what they say when they lack capacity
4. (Q13) Need to have a mechanism whereby a patient can appeal if they recover Capacity and want to take back control of their affairs. Many illnesses are EPISODIC e.g. Bipolar and psychosis. Loss of capacity may be severe enough to require an LPA during the episode but recover completely within weeks or months and may remain well for years before another episode. Also, there should be a data base for patients' advanced decisions in case the donee has strong conflicting views and may feel unable to put the patients requests forward (e.g. religious views about maintaining life at all cost)
5. (Q15) The bar should be even higher because " conviction or caution" is a fairly hard level to reach. We feel " The donee must not have had any prior history or acted in any way to cause harm to the person previously". (I.e. no history of any "safeguarding issues" towards that person)
6. (Q18) The person making the advance decision must be aware:
   1) An advance decision cannot be made to request or demand a specific treatment. These can only be expressed as "advanced wishes"
   2) That there is a difference between "treatment of life threatening conditions" which can be refused in advance and treatments that are "life sustaining" e.g. preventing dehydration with a drip, drying up secretions to ease breathing. Doctors may need to implement some treatments even if a patient requests "no treatments"
   3)There needs to be a central database for advanced decisions that can be accessed in an emergency by doctors as it can be hit and miss under certain circumstances as to whether this information is accessible when required.
7. (Q25) In the U.K. There is the RPR (relevant person representative) to support the person subject to DOLs.
   Also, how will the person appeal against DOLs?

END