

# **Code of Practice – Deceased organ and tissue donation in Guernsey**

This Code of Practice was issued by the Committee *for* Health & Social Care on 29<sup>th</sup> November 2022 under section 20 of the Human Tissue and Transplantation (Bailiwick of Guernsey) Law, 2020.

# **Contents page**

Code of Practice – Deceased organ and tissue donation in Guernsey	0
Introduction to this Code of Practice	3
Scope of the Code of Practice	4
Interpretation and general guidance	4
Research	6
Offences under the Organ Donation Legislation	7
Conditions on consent for organ and tissue transplantation	7
End of life care	8
Overview of deceased organ and tissue donation	9
Organ donation after death	9
Donation after Brainstem Death (DBD)	9
Donation after Circulatory Death (DCD)	9
Tissue donation after death	9
Consent	10
Overview	10
Recording a decision about organ and tissue donation	11
Role of the family	11
Taking account of the potential donor's faith and/or beliefs	13
Express consent	14
Establishing whether a potential donor made a decision in life - adults	14
The NHS Organ Donor Register as a source of consent	15
Appointed persons	17
The role of qualifying relationships in express consent situations	19
Establishing whether deemed consent applies	20
Consent for organ and tissue donation - children	20
Deemed consent	20
Circumstances in which consent can be deemed	20
Circumstances in which consent cannot be deemed	21
Residency	22
Ordinarily resident	23
Students	24
Prisoners	24
Those detained under the Mental Health (Bailiwick of Guernsey) Law, 2010	24
Other groups	25

Mental capacity	25
Sufficient period	26
Information that would lead a reasonable person to conclude that the potential do have consented	
Other considerations	28
Novel transplants	28
Use of organs and tissue across borders	28
Interventions prior to death	28
Preservation for transplantation after death	29
Law Officers of The Crown: HM Procureur & HM Comptroller	30
Status and use of the Code of Practice	30
Other advice and guidance	30
Appendix 1 – Excluded material	32
Appendix 2 – Qualifying relationships	33
Appendix 3 – Express consent for adults and children	34
Appendix 4 – exemptions to deemed consent	36
Glossary	37

#### Introduction to this Code of Practice

- This Code of Practice ('Code') is issued by the Committee for Health & Social Care ('Committee') to assist clinicians in the operational delivery of the provisions set out in the Human Tissue and Transplantation (Bailiwick of Guernsey) Law, 2020 ('the HT Law'), and its subordinate legislation, herein referred to as the 'Organ Donation Legislation.' This Code is issued under section 20 of the HT Law.
- 2. The subordinate legislation referred to in paragraph 1 includes:
  - a) The Human Tissue and Transplantation (Bailiwick of Guernsey) Law, 2020 (Commencement) Ordinance, 2022;
  - b) <u>The Human Tissue and Transplantation (Excluded Material) (Bailiwick of Guernsey)</u> <u>Ordinance, 2022</u>; and
  - c) The Human Tissue and Transplantation (Bailiwick of Guernsey) Regulations, 2022.
- 3. The Organ Donation Legislation should be read in conjunction with this Code.
- 4. The Organ Donation Legislation has force across the Bailiwick of Guernsey ('the Bailiwick'), which includes the islands of Guernsey, Alderney, Sark, Breqhou, Herm and Jethou. The Princess Elizabeth Hospital ('PEH') in Guernsey operates the Bailiwick's only Intensive Care Unit, Emergency Department and Operating Theatres and therefore tissue or organ donation activity should only be undertaken on the island of Guernsey.
- 5. Trust and confidence in the organ and tissue donation system requires widespread acceptance of its legitimacy. This means it is reliant not only on the lawful fulfilment of the donor's decision, but on the sensitive support of those close to the donor who are involved as part of end-of-life care. This requires clinicians to be sympathetic to the needs of individuals in every case where donation after death is a possibility.
- 6. A core principle underpinning this Code is that every effort should be made to establish the decision of a potential donor during his or her lifetime and to support the fulfilment of that individual's decision.
- 7. Notwithstanding the above, it is recognised that the circumstances surrounding donation vary from one case to another and it is therefore impossible to be prescriptive about what should happen in every case. Clinicians should reach a judgement about whether it is right for a donation to proceed having considered the information available to them. While the Organ Donation Legislation permits organ and tissue donation to take place in the presence of consent, it does not mandate that it must proceed.

8. Where the risk to public confidence might outweigh the benefits of donation proceeding, donation should not proceed even though it is legally permitted.

# Scope of the Code of Practice

- 9. This Code relates to organ and tissue donation where the organ or tissue is removed from a deceased person ('deceased donation').
- 10. As set out in paragraph 4, Organ Donation Legislation has force across the Bailiwick. However, as organ donation activity will only be undertaken on the island of Guernsey this Code applies, in particular, to the island of Guernsey.
- 11. In deceased donation, the removal, storage and use of organs and tissue for transplantation is governed by the Organ Donation Legislation. Before organs and tissue can be removed, stored or used for transplantation, appropriate consent must be obtained. This Code of Practice advises how the necessary consent requirements for this activity to be undertaken lawfully are met.
- 12. The Organ Donation Legislation sets out a deemed consent model whereby all adults are considered potential organ and tissue donors after their death unless they make a decision that they do not want to be a donor, they have appointed someone to make a decision on their behalf after death or they are an excepted adult.
- 13. Deemed consent only applies to certain organs and tissues. The list of organs and tissue excluded from deemed consent is set out in The Human Tissue and Transplantation (Excluded Material) (Bailiwick of Guernsey) Ordinance, 2022 and, for ease of reference, at Appendix 1.

# Interpretation and general guidance

- 14. This section explains terms that appear throughout the Code and terms that appear in the Organ Donation Legislation.
- 15. This Code provides guidance to the **authorised person** in relation to seeking consent for deceased donation. The individual leading the family approach for organ donation must be suitably trained and qualified, with sufficient knowledge and skills to sensitively answer any questions and time to support the family.
- 16. The Organ Donation Legislation sets out that an authorised person is:

Any person working in a specialist organ donation role as part of a National Health Service team or within the intensive care unit or the emergency department of the PEH so long as they are:

- (a) A nurse registered to practice with the Nursing and Midwifery Council; or
- (b) A doctor registered to practice with the General Medical Council and licensed to practice.
- 17. The Organ Donation Legislation requires that an **authorised person** confirms that there is express or deemed consent for the removal of organs and/or tissue. **Authorised persons** should record and certify that express or deemed consent is in place using standard National Health Service Blood and Transplant (NHSBT) paperwork. Where there is deemed consent, this record (signed by the **authorised person**) is the certificate of deemed consent required by the Organ Donation legislation.
- 18. In most cases the **authorised person** will be the Specialist Nurse involved in organ donation ('SNOD'), a Specialist Nurse in Tissue Donation ('SNTD') or a Specialist Requester ('SR').
- 19. For the remainder of this Code, the term **SNOD** is used to describe the **authorised person** and, for the avoidance of doubt, includes a **SNTD** and a **SR**. The Committee is of the opinion that the SNOD is the most suitable person to lead the family approach, working in collaboration with the treating medical team.
- 20. Any person involved in the retrieval of the donor's organs or tissue cannot act as the **SNOD**.
- 21. When the SNOD is required to make a difficult decision, or encounters an unusual situation, they should use the support available to them. This should include discussion with colleagues and, if necessary, a member of their senior management team to make the final decision.
- 22. The Organ Donation Legislation enables individuals who stood in a **qualifying relationship** to a potential donor to provide **express consent**. This Code makes clear the role of those in a qualifying relationship, listed in Appendix 2.
- 23. Where **express consent** is used, this refers to a decision to consent to organ and tissue donation that was given by either an individual in life, by an appointed person or someone in a qualifying relationship and, in the case of children, someone who had parental responsibility. Please refer to Appendix 3 for further information as to how express consent is established.
- 24. This Code references information that would lead a reasonable person to conclude that the potential donor would not have consented to organ and tissue donation. This broadly reflects the language of the Organ Donation Legislation and information used for this purpose can be provided by any family member or friend even if their relationship to the potential donor is not a qualifying relationship. For ease of reference, the Code refers to this wider group as family.

- 25. The Committee consider that the term **information** should be interpreted widely to include any insight into the decision of an individual regarding organ and tissue donation. This information may be in writing, but could equally be oral information, for example a report or recollection of a prior conversation held with the potential donor.
- 26. **Excluded material** refers to organs and tissue for which deemed consent cannot be used as a lawful basis for removal for transplantation. Material that is excluded from deemed consent is set out in <a href="https://doi.org/10.2002/jhear.2002">The Human Tissue and Transplantation (Excluded Material) (Bailiwick of Guernsey) Ordinance, 2022 and, for ease of reference, at Appendix 1.</a>
- 27. Donation of excluded material is permitted only with express and explicit consent. Consent can only be considered explicit when the excluded material is specifically referenced either in writing or verbally. The SNOD must not raise the issue of donation of excluded material and any discussion or reference to organ donation in general terms must not be considered to include excluded material. For the avoidance of doubt, a reference to a potential donor wishing to donate "all of their organs" cannot be considered to include excluded material because such a statement does not specifically name any excluded material.
- 28. **Ordinarily resident** refers to people living in the Bailiwick on a voluntary and properly settled basis. Ordinary residence can be of long or short duration but deemed consent will not apply unless the Bailiwick has been the potential donor's primary residence for at least 12 consecutive months immediately before their death.
- 29. Where **capacity** is referred to in the Organ Donation Legislation or this Code, this is interpreted to mean capacity under the <u>Capacity</u> (<u>Bailiwick of Guernsey</u>) <u>Law, 2020.</u>
- 30. **Sufficient period** refers to a sufficiently long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed due to the lack of capacity of the donor before death. In the Bailiwick, the Organ Donation Legislation sets out this period to be all or the majority of the 12 months immediately prior to death. The majority of 12 months is considered 6 (calendar) months plus 1 day.

#### Research

- 31. Use of organs and tissue for non-transplantation purposes, such as research, is outside the scope of deemed consent. Consent for research cannot be deemed.
- 32. Material removed when consent has been deemed for the purpose of transplantation, which cannot be used for this purpose, can be used for research if express consent for this purpose is obtained in accordance with the requirements of the HT Law.

# Offences under the Organ Donation Legislation

- 33. The Organ Donation Legislation establishes several offences, for which the maximum penalty is imprisonment and/or a fine.
- 34. In relation to organ and tissue donation, the offences are as set out in paragraphs 35-37.
- 35. Section 3 of the HT Law makes it an offence to remove human tissue from the deceased for transplantation purposes or teaching, research, or therapeutic purposes, or to store or use bodies or human tissue for transplantation purposes, without appropriate consent. Where there is consent to remove or use human tissue for one purpose, it may not be removed or used for another purpose without appropriate consent for that purpose.
- 36. Section 13 of the HT Law also makes it an offence to knowingly or recklessly make a statement or provide information that is false, deceptive or misleading in purported compliance with a condition, requirement or duty under the Organ Donation legislation, or where the information could be relied on to make a determination or carry out an activity under that legislation. An example is making a false representation that there is appropriate consent to undertake an activity.
- 37. A person does not commit an offence if they reasonably believed that appropriate consent was in place, or that the activity carried out was not one that required consent.

# Conditions on consent for organ and tissue transplantation

- 38. The Organ Donation Legislation recognises that individuals have the autonomous right to give or refuse consent to all or any of their organs or tissue being used for transplantation after their death.
- 39. Consent may be limited in a variety of ways. The Organ Donation Legislation does not prevent an individual from placing limits on their consent via the imposition of conditions, for example to participate in a particular research study or to donate specific organs and tissue and not others.
- 40. However, no organ should be transplanted under a form of consent which seeks to impose restrictions on the class of recipient of the organ, including any restriction based on a protected ground within the meaning of the <a href="Prevention of Discrimination (Guernsey)">Prevention of Discrimination (Guernsey)</a> Ordinance, 2022 or protected characteristic under the Equality Act 2010. This includes the recipient's disability, race (which includes colour, nationality and ethnicity), carer status, sexual orientation, religious belief, age, gender, marriage or civil partnership, pregnancy or maternity, religion or belief (which includes philosophical belief), language or sex.
- 41. This position partly reflects Article 14 of the European Convention on Human Rights as given effect by the <u>Human Rights (Bailiwick of Guernsey) Law, 2000</u> and the Human Rights

- Act 1998, and gives effect to the <u>Prevention of Discrimination (Guernsey) Ordinance, 2022</u> and the equality duty placed on public authorities by the Equality Act 2010.
- 42. The Committee supports the position of NHSBT whereby it does not accept organs from deceased donors where a restriction to those organs is attached.
- 43. The Committee does, however, support the consideration of a request that a deceased donor organ be allocated to a specific recipient in line with the most recent NHSBT policy.
- 44. It would be an offence to proceed with removing human tissue for transplantation purposes or teaching, research or therapeutic purposes, or storing or using human tissue from a deceased person for a transplantation purpose, or carrying out any other regulated activity, in the knowledge that a persisting condition on consent could not or would not be fulfilled, as valid consent would not be in place. Only the person who has attached the condition to the consent can put the condition aside.

#### Example

An individual decides to donate their organs after death, but only wants to do so on the condition that they are received by someone of the same ethnic origin. While there is nothing to prevent the individual expressing this as a condition, their organs could not be retrieved or transplanted while this condition remains in place.

#### End of life care

- 45. This Code should be read alongside the most recent applicable professional guidance regarding end-of-life care and organ and tissue donation.
- 46. This Code provides guidance on what constitutes lawful consent to organ and tissue donation after death has been diagnosed using either neurological or circulatory criteria. Diagnosis of death is a matter for clinicians providing end-of-life care.
- 47. Where a patient is undergoing end-of-life care, the clinicians providing that care, in discussion with the patient's family, may decide to withdraw life sustaining treatment. This would usually be expected to result in a death diagnosed using circulatory criteria and presents a possibility of donation after circulatory death (DCD).
- 48. Where the patient lacks capacity and has not made a prior advance decision to refuse treatment, any decision about the timing of withdrawal of life sustaining treatment or the institution of new therapies or treatment to enable organ donation to proceed must be taken in the patient's best interests. The patient's known decision about organ and tissue donation is one factor to include in the assessment of the patient's best interests. Any discussion with the family should be approached and conducted sensitively.

# Overview of deceased organ and tissue donation

#### Organ donation after death

- 49. There are two types of deceased donation which may be undertaken in Guernsey:
  - a) Donation after Brainstem Death (DBD); or
  - b) Donation after Circulatory Death (DCD).

For deceased donation to proceed two medical practitioners (neither of whom may be involved in the tissue removal or use) must certify that life is extinct.

#### Donation after Brainstem Death (DBD)

- 50. DBD is donation that takes place after a death which is diagnosed and confirmed using neurological criteria.
- 51. The patient's organ support, including mechanical ventilation, is maintained while consent is established or sought and (where applicable) arrangements are put in place for organ donation.

#### Donation after Circulatory Death (DCD)

- 52. DCD is donation that takes place after a death which is diagnosed and confirmed using circulatory criteria.
- 53. DCD may be either controlled or uncontrolled.
- 54. Controlled DCD describes organ retrieval which takes place after the planned withdrawal of life-sustaining treatment.
- 55. Uncontrolled DCD occurs following a sudden, irreversible cardiac arrest. **There are** currently no uncontrolled DCD programmes in the UK or Guernsey.

#### Tissue donation after death

- 56. Tissue donation is a possibility after death for both organ donors and those who are not suitable to donate organs.
- 57. Consent for tissue donation will be sought by a trained SNOD who is responsible for identifying the last known decision of the donor.
- 58. Deemed consent applies only to certain tissue. Excluded material is set out in <a href="The Human Tissue">The Human Tissue and Transplantation (Excluded Material) (Bailiwick of Guernsey) Ordinance, 2022</a> and replicated at Appendix 1.

#### Consent

#### Overview

- 59. The decision of a potential donor to consent to organ donation, or not as the case may be, is fundamental and if they made a decision to donate when they were alive, their consent cannot be deemed.
- 60. Bailiwick residents are encouraged to discuss their decision about organ donation with their family and friends.
- 61. The Organ Donor Register (ODR) enables Bailiwick residents to record their decision either to donate or not to donate organs and/or tissue after their death, or to nominate a representative to make a decision on their behalf.
- 62. Individuals may appoint one or more persons (an 'appointed person') to make a decision on their behalf about donation of their organs and tissue after they have died. There are specific requirements under the Organ Donation Legislation in relation to appointed person/s.
- 63. The HT Law repeals the Human Tissue (Bailiwick of Guernsey) Law, 1981, changing the legal consent mechanism for deceased donation, meaning that where an adult has neither:
  - a) made a decision to donate or not to donate organs or tissue before their death; nor
  - b) appointed someone to make a decision on their behalf after their death,
  - and there is no decision by someone in a qualifying relationship, consent for donation of their organs and tissue will be considered in place ('deemed consent').
- 64. This will be the case unless the donation involves excluded material, the potential donor is a child or an excepted adult, or information is provided by family that would lead a reasonable person to conclude that the potential donor would not have consented or proceeding with the activity would lead to severe distress in or severe conflict amongst the donor's family.
- 65. If any of those circumstances are present, then consent cannot be deemed and the donation must not proceed. The legal exemptions that apply to deemed consent are set out at Appendix 4.
- 66. A child is a person under the age of 18 years.

#### 67. An excepted adult is:

a) An adult who had not been ordinarily resident in the Bailiwick for a period of at least 12 months immediately before dying; or

- b) An adult who lacked the capacity to understand the notion of deemed consent for the majority or all of the 12-month period immediately before their death (this is regarded to be a **sufficient period** of lack of capacity, and thus to override the presumption of deemed consent).
- 68. Deemed Consent only applies to certain organs or tissue. Further information on this is set out at Appendix 1.
- 69. Where the potential donor is an excepted adult, consent cannot be deemed. In this case, donation can only proceed where express consent has been given, either by the potential donor before their death, by an appointed person or someone in a qualifying relationship.
- 70. Where the potential donor is a child, consent cannot be deemed and donation can only proceed where express consent has been given either by the potential donor before their death, by an appointed person, by someone in a qualifying relationship or a person with parental responsibility for that child. See Appendix 3 for further information on express consent.
- 71. A child aged 16 years or above may appoint one or more persons to represent them after death to deal with the issue of express consent (an 'appointed person').
- 72. Where consent is deemed, there are particular considerations about activities before death, which are outlined in the 'Preservation for Transplantation' section in paragraphs 189-198.
- 73. The existence of appropriate consent permits an activity to go ahead **but does not mandate that it must**.

#### Recording a decision about organ and tissue donation

- 74. The Organ Donation Legislation does not mandate how a person must record their decision about organ and tissue donation.
- 75. This means that it is for the individual to decide how they wish to do this. Options might include registering their decision on the ODR, telling a friend or family member, or recording it in writing.
- 76. The ODR is checked in every potential case of organ and tissue donation and the information stored is communicated to the family.

#### Role of the family

77. The family play a crucial role in the donation process. The nature of the role with respect to consent will depend on several factors including whether consent has been expressed by the potential donor, whether the circumstances are such that consent may be deemed, or whether a person in a qualifying relationship will be asked to make the decision. The

- role of the family should be to help establish the decision of the individual regarding donation.
- 78. Sensitive communication and engagement with the family by the SNOD and medical team play an essential part in supporting the family throughout the donation process.
- 79. There are many factors that need to be considered in deciding whether donation can proceed, based on the circumstances of each case. Each stage of organ donation, from intensive care admission to organ retrieval, is comprehensively set out in NHSBT's guide 'The Journey through Intensive Care and the Gift of Organ Donation' that may provide useful information for families.
- 80. If the potential donor has expressed consent, the SNOD should discuss this decision with the family. The family will be asked to provide additional and detailed medical and social history about the potential donor. This is not part of the consent process, but a necessary part of clinical practice so that decisions can be made about the suitability of organ and/or tissue donation considering all the relevant information. This information should not be sought from the family until consent to donation has been established.
- 81. If the potential donor has expressed consent, but no family is available to provide medical and social history, consent would still be in place and donation could still go ahead. However, this requires a clinical judgement and risk assessment by the medical team to protect any recipients of organs or tissue. The medical team should also take account of any conditions placed on consent by the donor and assess whether these can be fulfilled before reaching the final decision about whether to proceed.
- 82. If there is a decision on the ODR that the person did not want to be a donor, this should be communicated to the family by the SNOD or medical team. Donation must not proceed unless the family has information that the person had expressed consent to donation which superseded the individual's earlier decision.
- 83. If there is no recorded decision and the potential donor (at the time the donor was 16 years of age or older) appointed a person to make the decision for them, any decision on consent must be made by that appointed person. The role of the family in circumstances where the appointed person gives consent is equivalent to that where the donor themselves had expressed consent.
- 84. If the appointed person cannot be reached, renounces the appointment or is unable to make a decision, express consent may be given by someone in a qualifying relationship, in the case of an adult donor, and in the case of a child donor by a person who had parental responsibility for the child immediately before the child's death or if no such person exists,

- someone in a qualifying relationship. In such circumstances, the role of the family is the same as that in other circumstances where consent may be deemed.
- 85. If there is no decision by the potential donor, they have not appointed a person to deal with consent and they are not a child or an excepted adult, then consent may be deemed. The SNOD should explain this to the family and have a sensitive discussion to best support their needs and to facilitate donation. In these circumstances, the Organ Donation Legislation allows for family to provide information that would lead a reasonable person to conclude that the person did not want to be a donor. If such information is provided, then donation must not proceed.
- 86. If the family of the potential donor object to the donation where appropriate consent (whether express or deemed) is in place, the SNOD should discuss the matter sensitively with them to understand and, if appropriate, attempt to overcome their concerns.
- 87. Although the family cannot revoke legally valid consent, their views will always be considered throughout the donation process and will have a strong influence on whether donation proceeds. The presence of valid consent is sufficient for donation to be lawful **but does not mandate that it must proceed**.
- 88. Family members may have differing views about donation when appropriate consent is in place. The SNOD, in discussion with the medical team, should provide the family with the appropriate time and information they need to come to an agreement.
- 89. In a situation where consent could be deemed but there is no family to speak with to establish the individual's last known decision, **donation should not proceed**. The Committee considers that the risks to public confidence of proceeding in these circumstances would outweigh the benefits.

#### Taking account of the potential donor's faith and/or beliefs

- 90. Since December 2018, when registering a decision to consent to organ and tissue donation on the ODR, individuals have been able to record whether their faith and/or beliefs are important to them in relation to organ donation.
- 91. For ODR registrations prior to December 2018, the SNOD should explore whether faith and/or beliefs were important to the potential donor through conversations with the family.
- 92. Where a potential donor has indicated on the ODR that faith and/or beliefs are important to him or her, the SNOD must explain this to the potential donor's family and discuss the potential donor's faith and/or beliefs with respect to organ and tissue donation. The SNOD

- should answer any questions and seek further guidance and support from faith leaders if required.
- 93. Where an individual has registered as a potential donor, but their family disagrees that donation is consistent with the potential donor's faith and/or belief, the SNOD should explore any issues raised by the family and support them to address any concerns. Where indicated, SNODs can facilitate consultation with religious and non-religious leaders to provide counsel or clarification on donation. For example, the family may wish to ensure appropriate end of life rituals are followed or that any religious obligations are observed should donation take place. For the avoidance of doubt, any such religious obligations would not override the prohibition against imposing restrictions on the class of recipient of the organ or tissue.
- 94. The PEH has a chaplaincy service representing different faiths, which can help support families.

#### **EXAMPLE**

A potential donor registered a decision to consent to donate all organs and tissue on the ODR. They have also recorded that their faith or beliefs are important to them in relation to organ and tissue donation on the ODR. The SNOD should explain this to the potential donor's family and discuss the potential donor's faith, beliefs and values. The SNOD should support the family and answer any questions they may have. The SNOD may also seek further guidance and support on behalf of the family from faith or belief representatives if required.

# **Express consent**

#### Establishing whether a potential donor made a decision in life - adults

- 95. The Organ Donation Legislation establishes the principle that the decision to consent to deceased donation rests primarily with the potential donor. As such, the potential donor's valid consent where this is recorded, or last known decision as expressed to the family, should form an integral part of end-of-life care planning.
- 96. The Organ Donation Legislation makes clear that where an adult with capacity made a decision to consent to deceased donation, such consent is sufficient for donation to be lawful but does not mandate that it must proceed.
- 97. Where an adult with capacity made a decision not to consent to deceased donation, donation must not proceed as consent is not in place.
- 98. In every case where organ and tissue donation is a possibility, the SNOD should determine whether the potential donor has made a decision about organ and tissue donation. The SNOD should seek to establish the most recent decision of the potential donor in conversation with their family, i.e. the decision in force immediately before their death.

99. Under the Organ Donation Legislation, certain organs and tissue are excluded from deemed consent and will require express, and explicit, consent for donation to proceed (see Appendix 1).

#### The NHS Organ Donor Register as a source of consent

100. The ODR operates throughout the UK and Channel Islands to allow individuals to record their decision about organ and tissue donation or appoint a person to represent them after their death to deal with the issue of express consent.

#### 101. The ODR allows the following decisions to be recorded:

- a) Consent to donate all organs and tissue after death;
- b) Consent to donate **some** (specified) organs and tissue after death; or
- c) Not to consent to donate organs and tissue after death.
- 102.NHSBT provides the form 'Appointing a representative to make organ donation decisions on your behalf' to allow potential donors to appoint an appointed person. Completion of this form is recognised as a valid appointment of an **appointed person** under the Organ Donation Legislation.
- 103.So long as a potential donor registered their decision voluntarily, had the information they needed to make the decision to register and had mental capacity when they registered, then the decision recorded on the ODR constitutes valid and appropriate consent at the time of registration. For children this is a test of competence, for adults it is capacity.
- 104.A legally valid decision from the potential donor is sufficient to allow organs and tissue to be retrieved for transplantation where they have decided to donate. Similarly, in circumstances where they have decided not to donate, donation cannot proceed. There is no legal right for anyone in a qualifying relationship to revoke a legally valid decision to give or withhold consent.
- 105. If the recorded decision was not to consent to organ and/or tissue donation, then this can be communicated to the family. If the family believe that this was not the most recent decision of the potential donor, the SNOD should obtain information from the family about the potential donor's more recent decision to consent to organ donation.
- 106.If it is clear to the SNOD that the potential donor had changed their mind, having previously recorded a decision not to consent on the ODR, then donation could proceed.

#### **EXAMPLE**

A potential donor has registered their decision not to consent to organ and tissue donation on the ODR. The SNOD or clinician will inform the family that a decision not to consent to organ and tissue donation exists and that it will be honoured. The family believe that there is a more recent decision to donate. The SNOD or clinician should obtain information from the family of the potential donor's more recent decision to consent to organ and tissue donation.

107. If the family believe that a potential donor who was registered on the ODR had revoked their decision to consent to deceased donation, the SNOD should obtain information from the family about the potential donor's more recent decision to refuse consent to donation.

#### **EXAMPLE**

A potential donor registered a decision to consent to donate all organs and tissue on the ODR. The potential donor's mother says that her son subsequently changed his mind about donation prior to his death. The SNOD will have a sensitive discussion with the potential donor's mother to understand the context of the information that is presented, by exploring with her the son's decision to change his mind. The discussion will focus on what the potential donor decided, as his last known decision will have primacy.

- 108.In making a decision about whether there is valid consent to proceed with donation, the SNOD must make a judgement about the reliability of the information provided. It may be helpful to consider the following:
  - a) Is the information in writing, signed and dated by the potential donor and witnessed? If this is the case, then this is likely to be express consent by the potential donor (it is important to note that revocation of a decision to consent, or a decision not to consent, does not need to be in writing, but that a written revocation would be considered more reliable).
  - b) Is the information given orally? If so, can it be confirmed by more than one person?
  - c) Is the information presented as reflecting the views of the potential donor, or the views of the family? If the latter is the case, then this is likely to constitute an objection rather than information about the potential donor's decision.
- 109. Where valid consent has been given by the potential donor, but the family object to organ and tissue donation proceeding, they should be sensitively supported to respect the potential donor's consent to ensure his or her decision is fulfilled. The family's objection does not nullify valid consent from the potential donor.

#### **EXAMPLE**

A potential donor registered a decision on the ODR to consent to their organs and tissue being donated for transplantation. However, the family do not want tissue donation to proceed. The SN will explore the family's concerns and answer any questions they may have. The discussion will focus on what the potential donor had decided. As the potential donor's consent is valid and their views have primacy, donation could be lawful but this does not mandate that it must proceed.

- 110. The existence of appropriate consent permits donation to proceed but does not mandate that it must. The final decision about whether to proceed rests with the SNOD and the medical practitioners caring for the patient, in conversation with the family.
- 111. Those close to the patient will be involved in making best interests decisions for the patient who lacks capacity when DCD is a possibility. Consent via the ODR is one factor to consider when assessing whether interventions to facilitate organ and tissue donation are in the potential donor's best interests.

#### Appointed persons

- 112. If the potential donor's decision is not known and they were an adult who had appointed a person to make a decision regarding deceased donation on their behalf, then a decision on consent must be given by that appointed person.
- 113. The name and contact details of the appointed person/s may have been recorded via NHSBT's form *Appointing a representative to make organ donation decisions on your behalf* and the SNOD should contact them to ask them to make a decision on behalf of the potential donor.
- 114.A child under the age of 16 years <u>cannot</u> act as an appointed person under the Organ Donation Legislation. A child aged 16 or over <u>may appoint</u> a person to represent them after death to deal with express consent.
- 115.It may be the case that a potential donor appointed a person/s but did not use the form or tell their family about it. It is recognised that it is not practical for the SNOD to make extensive checks to establish whether a potential donor appointed a person/s. If, having asked the family, the SNOD is not made aware of an appointed person/s at this stage, it is reasonable to proceed as if no person had been appointed.
- 116.If the appointment was made orally, the SNOD should check that the appointment was witnessed by at least two people present at the same time. This can be confirmed either by asking the two witnesses, or by producing a document signed by the two witnesses confirming that they witnessed the appointment.

- 117. If the appointment was made in writing, the SNOD should be assured that one of the statements at a) to d), below, is true:
  - a) The document making the nomination was signed by the potential donor in the presence of a witness who confirmed the signature; or
  - b) It was signed by another person at the direction of, and in the presence of, the potential donor, and in the presence of a witness who confirmed the signature; or
  - c) It was contained in the will of the potential donor, and that will was made lawfully; or
  - d) It is an appointment made in a lasting power of attorney concerning the person's health and welfare under the Capacity (Bailiwick of Guernsey) Law, 2020
- 118. Where a valid lasting power of attorney (LPA) exists in relation to the health and welfare of the potential donor, it is possible that the LPA includes the authority to make a decision in relation to deceased organ donation. Where this authority exists, it is considered to be a valid appointment under section 9 of the HT Law for the purpose of dealing with express consent.
- 119.If more than one person has been appointed, only one of them needs to give consent unless the terms of the appointment specify that they must act jointly.
- 120.If the appointment requires that multiple representatives must act jointly, this means that all representatives must agree for consent to be given. In these circumstances, if one representative cannot be contacted then the other representative(s) cannot give consent and consent may be deemed.
- 121. There will be no consent if an appointed person is not available to give consent under the appointment. In such cases, the appointment may be disregarded. This includes situations where it is not reasonably practicable to communicate with the appointed person within the time available or if they are not available.
- 122. For the avoidance of doubt, a guardian under any custom of law cannot do any of the following by virtue only of being the guardian of the potential donor:
  - a) give express consent on behalf of the potential donor,
  - b) appoint one or more persons to represent the potential donor after death to deal with the issue of express consent for the purposes of this Law, or
  - c) otherwise deal with the issue of express consent for the potential donor.

#### The role of qualifying relationships in express consent situations

- 123. Express consent may be given by someone who was in a qualifying relationship with the potential donor immediately before their death.
- 124. The Human Tissue and Transplantation (Bailiwick of Guernsey) Law, 2020 includes at section 25(1) a list of qualifying relationships. For ease of reference, this list is replicated at Appendix 2 of this Code. Appendix 2 also ranks these relationships for the purposes of paragraphs 128 and 129.

#### 125.A person is another person's civil partner if:

- a) they were in a civil partnership which exists under or by virtue of the Civil Partnership Act 2004 (or equivalent legislation in force anywhere in the United Kingdom, the Bailiwick, the Bailiwick of Jersey or the Isle of Man);
- b) they were in a same sex relationship registered outside the British Islands which is entitled to be treated as a civil partnership under the Civil Partnership Act 2004 (or equivalent legislation in force anywhere in the British Islands); or
- c) they lived as partners (whether same sex or not) in a relationship akin to marriage or civil partnership and neither of them is a spouse or civil partner of any other person.
- 126.A long-standing friend is not defined in the legislation. It does not necessarily require a specified period attached to the friendship. Whether someone is a long-standing friend will depend on all the facts and circumstances and should be considered on a case-by-case basis. The SNOD may ask questions and/or request information as necessary to establish what degree of friendship existed and whether it could reasonably be considered long standing.
- 127. Where there is disagreement between people in different positions on the ranked qualifying relationship list, it is recommended that the SNOD provides those people with the time and information they need to come to an agreement. If it is not possible to reach an agreement, a decision on consent should be obtained from the person whose relationship to the potential donor is accorded the highest rank on the list. The decision whether or not to proceed lies with the SNOD, with the necessary decision making support from senior management, in conversation with the family.
- 128.In a situation where agreement cannot be reached between people of the same rank, it is lawful to proceed with the express consent of just one of those people. This does not mean that the consent of one person must be acted on, and the SNOD will need to carefully consider the emotional impact of any decision on the wider family.

#### Establishing whether deemed consent applies

- 129. If the potential donor has neither made a decision in relation to organ and tissue donation nor appointed a person, then a decision must be made as to whether deemed consent may apply.
- 130. In the Bailiwick, deemed consent does not apply to:
  - a) children under 18 years of age;
  - b) excepted adults; and
  - c) donation of excluded material
- 131.If deemed consent does not apply, move to section on 'The role of qualifying relationships in express consent'.
- 132. If deemed consent does apply, move to section on 'Deemed Consent'.

#### Consent for organ and tissue donation - children

- 133. The position for a child, who was competent to reach a decision before they died and consented to organ and tissue donation taking place after their death, is legally no different from that of an adult. If the child was competent when making the decision, the child's consent is sufficient to make the removal, storage or use of their organs and tissue for transplantation lawful. A child who is 16 years of age or older is presumed to be competent.
- 134.If a child did not make a decision, or was not competent to do so, the Organ Donation Legislation makes clear that in this instance consent for organ and tissue donation will be that of a person with parental responsibility for the child immediately before they died. The consent of only one person with parental responsibility is sufficient. Where no person had parental responsibility for the child immediately before they died, appropriate consent will be that of someone in a qualifying relationship to the child.
- 135. Consent for organ and tissue donation from a child under 18 years of age cannot be deemed.
- 136. A child aged 16 years or over can appoint a person (an 'appointed person') to make a decision regarding organ and/or tissue donation.

#### Deemed consent

#### Circumstances in which consent can be deemed

137.In cases where the decision of a potential donor regarding consent for organ and tissue donation cannot be established either from the ODR or from family, or where an

- appointed person has not been appointed, then consent can be deemed, (unless an exemption to deemed consent, set out in Appendix 4, applies).
- 138. There may be occasions where a potential donor has neither recorded a decision nor appointed a representative and, despite the efforts of the SNOD, there is no family in existence or available for the SNOD to speak with. In these circumstances, **donation should not proceed**.
- 139. When SNODs are required to make a difficult decision, or encounter an unusual situation, they should discuss the situation with colleagues and if necessary, contact a member of the senior management team to make a final decision. This ensures consistency of approach and high-quality decision making.
- 140.If a person appointed another person to make a decision, the decision of the appointed person should be acted upon. If the appointed person cannot be contacted in time to make a decision, or is unable to make a decision, then consent can be given by someone in a qualifying relationship. The SNOD should make every reasonable effort to contact the appointed person and the family should be given the opportunity to provide further information.

#### **EXAMPLE**

A potential donor has lived and died in Guernsey. The potential donor: has not recorded a decision about organ and tissue donation on the ODR or expressed a decision in writing or verbally to family; is not an excepted adult, and there is no information that would lead a reasonable person to believe they did not want to be a donor.

The potential donor's consent could be deemed, and donation could lawfully proceed.

#### Circumstances in which consent cannot be deemed

141. Consent cannot be deemed if:

- a) the donor is an excepted adult or a child;
- b) the donor has made a decision not to consent and that decision is still in effect;
- a family member provides information that would lead a reasonable person to conclude that the potential donor would not have consented;
- d) the transplantation activity involves excluded material as specified in <a href="The Human Tissue">The Human Tissue and Transplantation (Excluded Material) (Bailiwick of Guernsey) Ordinance, 2022;</a> or
- e) proceeding with the transplantation activity would lead to severe distress in or severe conflict amongst family.

Please see **Appendix 4** for further information on exemptions to deemed consent.

- 142.It is for the SNOD, in discussion with medical and nursing staff, to use their clinical judgement to determine severe distress or conflict.
- 143. If a potential donor made a decision to donate their organs and tissue when they were alive, they have given express consent. If their decision was to refuse to consent, their consent cannot be deemed.
- 144.In circumstances where consent cannot be deemed, consent should be sought from a person in a qualifying relationship.
- 145.In a situation where consent could be deemed but there is no family to speak with to establish the individual's last known decision, **donation should not proceed**.

#### Residency

- 146. For deemed consent to apply, the potential donor must have been ordinarily resident in the Bailiwick for 12 calendar months immediately prior to their death. For the purposes of deemed consent, the time of death is taken to be the date on which death is confirmed by the two certifying medical practitioners.
- 147. For the purposes of the Organ Donation Legislation, 'the Bailiwick' means the islands of Guernsey, Alderney, Sark, Herm and Jethou.
- 148.In most cases a SNOD will be able to establish where the potential donor lived, and whether they were ordinarily resident at an address or several addresses in the Bailiwick, either from medical records or through discussions with family.
- 149.If there is reasonable cause for doubt and the potential donor cannot safely be assumed to be ordinarily resident in the Bailiwick, then consent should not be deemed.

#### **EXAMPLE**

An adult dies in hospital in Guernsey on 15 January. Their death is diagnosed and confirmed using neurological criteria. The SNOD establishes by speaking to the family that the potential donor moved to the Bailiwick on 17 January of the previous year. Deemed consent does not apply, as the potential donor had not lived in the Bailiwick for 12 calendar months prior to their death. Consent may be given by an appointed person or someone who was in a qualifying relationship with the deceased person immediately before their death.

- 150. The 12-month period test does not involve counting the number of days a potential donor had lived in the Bailiwick. Rather, it is necessary to establish that a potential donor had been ordinarily resident in the Bailiwick for at least twelve calendar months.
- 151.In some cases, it may not be possible to establish the exact date on which a potential donor started living in the Bailiwick. For example, their family may not be able to remember exactly when they moved to the Bailiwick, but do know it was within the last 10-14 months.
- 152. When this is the case and there is no clear information available to confirm the time since the potential donor started living in the Bailiwick, consent should not be deemed.

#### Ordinarily resident

- 153.A potential donor will be 'ordinarily resident' in the Bailiwick when that residence is adopted voluntarily and for settled purposes as part of the regular order of their life for the time being. Ordinary residence can be of long or short duration, but deemed consent will not apply unless someone has been ordinarily resident in the Bailiwick for at least 12 months immediately before dying. While there is no general legal definition of 'ordinary residence' in the Bailiwick, the criteria which should be established are:
  - a) The residence was adopted voluntarily. It will be rare for a person not to be in the Bailiwick voluntarily. For example, the fact that the potential donor chose to come to the Bailiwick at the request of an employer, rather than seek another job, is unlikely to make their presence in the Bailiwick involuntary.
  - b) The potential donor was resident for settled purposes. There must be an identifiable purpose for their residence here with a sufficient degree of continuity to properly be described as settled. Business, education, employment and family can all provide a settled purpose, but this list is not exhaustive. There may be one purpose or several, and it may be for a limited period.
  - c) The potential donor's residency in the Bailiwick supported the regular order of their life for the time being. There is no requirement for any person to be living in the Bailiwick permanently or indefinitely. The potential donor may have had temporary absences from the Bailiwick and still be considered ordinarily resident. It is also possible to be ordinarily resident in more than one country.
- 154. These qualities must be assessed on a case-by-case basis weighing up the relevant information. Whether the requirements have been satisfied will primarily be a question of fact. In many cases, the SNOD will be able to establish easily whether the potential donor's residence was characterised by the requirements above. When ordinary residence is initially unclear, it is recommended that there is a sensitive discussion with

family to gain more information about where the potential donor would have considered themselves ordinarily resident.

- 155. When a SNOD has reasonable cause to doubt that the potential donor was ordinarily resident in the Bailiwick, then consent should not be deemed.
- 156. The SNOD should also seek advice from members of Health and Social Care staff to establish whether the potential donor is ordinarily resident in the Bailiwick.

#### **EXAMPLE**

A potential donor worked in the Bailiwick and lived there four nights a week, spending the other three nights at their family home in London. The potential donor dies in the Bailiwick. The SNOD should ask questions of the family to establish where the potential donor would have considered themselves ordinarily resident. It will then be for the SNOD to weigh up the information to establish whether the potential donor was ordinarily resident in the Bailiwick. If the SNOD establishes that the potential donor considered London to be their home and the Bailiwick to be their place of work only, consent could not be deemed.

#### **EXAMPLE**

Two friends who are ordinarily resident in Wales go on a holiday to the Bailiwick. During the holiday, one of the friends dies in hospital. Deemed consent does not apply as the person was not ordinarily resident in the Bailiwick. Consent may be given by an appointed person or someone who was in a qualifying relationship with the person immediately before their death.

#### Students

157. There are no universities or schools where children live within premises while being given formal instruction in the Bailiwick. But a student over the age of 18 years could be studying in a local school in the Bailiwick while being ordinarily resident in the Bailiwick.

#### **Prisoners**

158.A person who is in prison cannot be considered as residing in the Bailiwick voluntarily, and therefore cannot be considered ordinarily resident in the Bailiwick during their time in prison. This includes prisoners who normally live in the Bailiwick and who are in prison in the Bailiwick. People in prison cannot have their consent to organ and tissue donation deemed. This includes prisoners released on licence where a condition of their licence is that they remain living in the Bailiwick.

#### Those detained under the Mental Health (Bailiwick of Guernsey) Law, 2010

159.A person who is the subject of an assessment order, a treatment order or a community treatment order granted under the Mental Health (Bailiwick of Guernsey) Law, 2010 should not be considered to be residing voluntarily in the Bailiwick, even if the Bailiwick is their usual home, and therefore should not have their consent to organ and tissue donation deemed.

#### Other groups

- 160. There are also those who live in the Bailiwick but not for a settled purpose and/or as part of the regular order of their lives. For example, hospitality or other seasonal workers who spend a portion of their time in the Bailiwick but who do not regard it as their home. It is for the SNOD to ask questions of family to establish whether the person was ordinarily resident on a case-by-case basis.
- 161. Armed forces personnel are not posted in the Bailiwick.
- 162. Where the 'ordinarily resident' test is not satisfied, donation cannot proceed on the basis of deemed consent.

#### Mental capacity

- 163. Deemed consent does not apply to people who, for a sufficient period before their death, lacked the capacity to understand that consent to donation can be deemed.
- 164. Where the potential donor does not have capacity, interventions before death are governed by the Capacity (Bailiwick of Guernsey) Law, 2020, rather than the Organ Donation Legislation.
- 165. If a potential donor lacked capacity for a sufficient period before their death, then the person is an excepted adult, and their consent cannot be deemed. Therefore, express consent should be sought from an appointed person or a person in a qualifying relationship.
- 166.If, at the point at which a potential donor lost capacity, deemed consent did not apply to them, for example, they were a child or had not ordinarily resided in the Bailiwick in the preceding 12-month period, then transplantation activity should not be carried out on the basis of deemed consent.
- 167.In some cases, it will be evident that a potential donor lacked capacity for a sufficient period before their death as they may, for example, have been suffering from a persistent disorder of consciousness (coma, vegetative or minimally conscious state).
- 168.In other cases, to establish whether a potential donor lacked capacity for a sufficient period before their death, the SNOD should take the following steps:
  - a) Check the medical records of the potential donor for a history of conditions or illness, which may have affected the potential donor's capacity to understand that consent could be deemed. It is important to note that a record of an episode, or episodes, of such an illness would not necessarily mean that a potential donor

- lacked capacity to understand that consent could be deemed. However, it should prompt further investigation by the SNOD.
- b) If there is no indication in the medical records of a condition or illness, which may have impacted the potential donor's capacity to understand that consent could be deemed, or any assessment of the potential donor's capacity to understand this, the SNOD should document this on the consent form and/or medical records.
- c) If there is an indication in the medical records of a condition or illness that may have affected the potential donor's capacity to understand that consent could be deemed, the SNOD should undertake further investigations of the condition or illness. The issue of mental capacity should be raised by the SNOD when speaking to the family to ascertain if the potential donor had the capacity to understand that consent to organ and tissue donation could be deemed.
- d) Where there is information about a condition that may have affected the potential donor's capacity to understand that consent could be deemed, in most cases it will be the family who are able to provide the SNOD with the most accurate information as to whether the potential donor had the capacity to understand that consent to organ and tissue donation could be deemed. The SNOD should ask the family whether they believe the potential donor had the capacity to understand that their consent could be deemed. This may be a detailed discussion, and if at the end of this the SNOD is not satisfied that the potential donor had the capacity to understand that consent could be deemed, then consent should not be deemed.

169. If the potential donor had been in hospital for some time, it may be appropriate to speak to a member of the team caring for them about their capacity.

#### Sufficient period

- 170.Under the Organ Donation Legislation, the sufficient period, during which the potential donor would need to have the requisite capacity, is all or the majority of the period of 12 months immediately before dying. A majority of the 12 month period is considered 6 (calendar) months plus 1 day.
- 171. The lack of capacity to understand that consent can be deemed for a sufficient period only negates deemed consent. If the potential donor had made a decision to consent, or not as the case may be, while they had capacity to make that decision then that decision remains valid regardless of a subsequent loss of capacity.

# Information that would lead a reasonable person to conclude that the potential donor would not have consented

- 172.If a potential donor is not a child or an excepted adult, and they had neither made a decision in life nor appointed a person who had given consent under that appointment, then their consent to organ and tissue donation may be deemed (subject to the exemptions set out in Appendix 4).
- 173. When this is the case, the SNOD should have a discussion with the family and give them the opportunity to provide information that would lead a reasonable person to conclude that the potential donor would not have consented.
- 174. When there is no family found or available, donation should not proceed.
- 175. Any family can provide information to show that the potential donor would not have consented. This means that, in practice, it is the quality of the information that should be considered by the SNOD, and not the relationship to the potential donor of the person presenting it.
- 176. When there is written information from the potential donor, and this is signed by a witness, this would form the decision of the potential donor and so consent should not be deemed.
- 177. When there is written information from the potential donor that has not been witnessed, it will be for the SNOD to decide whether this is information that would satisfy a reasonable person.
- 178. Where there is other oral information, it will be for the SNOD to decide whether this is information that would satisfy a reasonable person.
- 179. The reasonable person test involves the person making the assessment (in this case the SNOD and medical team), deciding how much reliance to place on the information presented.
- 180.In order to assess the reliability of the information presented, the following questions may help the SNOD:
  - a) Is the information presented as reflecting the views of the potential donor, or the views of the family? The test requires that information presented must be the potential donor's view.
  - b) Is the information oral? If so, is it confirmed by more than one person?

- c) How recent is the information? The SNOD should establish when the record was made, or when the conversation took place, and note this in the potential donor's medical record or other appropriate document.
- d) How well does the person providing the information know the potential donor? It is not always the case that a person knows someone well simply because they are related.
- 181.Information that the potential donor was not aware that deemed consent affected them is not sufficient, on its own, to lead a reasonable person to conclude that the potential donor would not have consented to organ and tissue donation.

#### Other considerations

#### **Novel transplants**

- 182. Deemed consent only applies to certain organs and tissue: the list of organs and tissue excluded from deemed consent is set out in <a href="The Human Tissue and Transplantation">The Human Tissue and Transplantation</a> (Excluded Material) (Bailiwick of Guernsey) Ordinance, 2022 and replicated in Appendix 1. Transplantation of these organs or tissue are new and are usually at a research or practical evaluation stage, or have gone through research and service evaluation stages, but are still rare and unusual. An example of this would be face transplantation.
- 183. For the organs and tissue on this list, express and explicit consent must be given for the removal, storage or use for the purpose of transplantation to be lawful. Paragraph 27 provides information as to express consent that is explicit for the purpose of donation of excluded material.

#### Use of organs and tissue across borders

- 184.Organs and tissue removed when consent in the Bailiwick has been deemed can be lawfully transplanted into patients in England, Wales, Northern Ireland and Scotland (providing all other statutory and regulatory requirements have been met).
- 185. This also means that organs and tissue removed in Guernsey for the purpose of transplantation when consent has been deemed can be stored, used, processed and distributed lawfully across the whole of the UK and Europe.

#### Interventions prior to death

186. The Organ Donation Legislation does not address the matter of steps which may be taken prior to the death of a potential donor who may become a donor after death is diagnosed and confirmed using circulatory criteria.

- 187. Where the potential donor does not have capacity, interventions before death are governed by the Capacity (Bailiwick of Guernsey) Law, 2020, rather than the Organ donation Legislation.
- 188. The taking and storage of blood samples from a potential donor is necessary to ensure that the organ and tissue can be used for transplantation. Blood samples should only be taken in cases where consent for donation has been given (by the potential donor, an appointed person or someone in a qualifying relationship) or consent has been deemed (which could only occur following discussion with the family).

#### Preservation for transplantation after death

- 189. The Organ Donation Legislation allows for minimum steps to be taken to preserve parts of a potential donor's body when it is, or may be, suitable for transplantation, but consent or the absence of consent has not yet been established.
- 190. These provisions relate only to the preservation of a potential donor's body after their death.
- 191. For preservation to be lawful, the body of the potential donor must be lying in a hospital, nursing home, mortuary or other institution in Guernsey.
- 192. The steps which can be taken to preserve the organs within the body for transplantation must be minimal and it is a requirement that the least invasive procedure is used.
- 193. Whether a procedure meets this test will depend on the facts of the case, including how invasive it is, when consent might be obtained, and how the family would perceive it.
- 194.In all cases, steps should therefore be taken as soon as possible to establish the decision on donation, or where this is unknown, whether consent can be deemed. Where possible, appropriate consent for donation should be established before the preservation process begins, or alternatively consent for the preservation process prior to donation.
- 195. The taking and storage of blood samples from a deceased person is necessary to ensure the preserved organ and tissue can be used for transplantation. Blood samples should only be taken in cases where consent for donation has been given (by the deceased, their appointed person or someone in a qualifying relationship) or consent has been deemed (which could only occur following discussion with the family).

#### 196. If it is established, either:

a) that express consent has not been given, and that consent cannot be deemed, or

- b) a decision has been made not to donate,
- then the steps taken to preserve organs for the purpose of transplantation should cease or be withdrawn promptly.
- 197. An area of development in retrieval surgery is organ recovery. During the dying process organ injury can occur. Organ recovery seeks to maintain and improve viability leading to high quality organ transplants, as well as using organs that previously would not have been considered transplantable. Organ recovery procedures use machine perfusion of the organs, which takes place either in the donor after death (in situ) or on the organ following retrieval from the donor in specialist machines (ex situ).
- 198. These organ preservation techniques cannot be considered minimum steps and must only be used only where appropriate consent to donation is in place.

### Law Officers of The Crown: HM Procureur & HM Comptroller

- 199.Organ Donation Legislation prohibits a person from giving, or acting on, consent where the person is aware or has reason to believe that a post-mortem or inquest might be required by HM Procureur (this term includes HM Comptroller).
- 200. Where medical practitioners are unable to state a cause of death, or otherwise suspect negligence, or that a crime has been committed, they must notify the death to the Law Officers of the Crown ('Law Officers') (and to the Police) who may authorise a post mortem examination. A sudden or unexpected death should be discussed with the Law Officers and will not necessarily require a post mortem examination, but if there is no obvious cause of death meaning that the medical practitioners are unable to sign a death certificate in accordance with legal requirements, a post mortem examination will be directed by the Law Officers. In such cases, authorisation from HM Procureur must be sought before any transplantation activities can be undertaken, or steps can be taken to preserve the organs within the body of the person.

### Status and use of the Code of Practice

201. Throughout the Code, the word 'must' applies to all legal requirements derived from primary and secondary legislation. We use the word 'should' when providing advice on how to meet these requirements or on recommended practice.

# Other advice and guidance

202. This Code should be read alongside other relevant advice, guidance and legislation which is either referenced in the text or available on Health and Social Care's operational policy library - PoliPlus. The Code may also refer to guidance which has been produced by other organisations. The Committee is not responsible for the content of others' guidance but

does recommend that practitioners follow any best practice guidance in the course of their professional duties.

# Appendix 1 – Excluded material

The Human Tissue and Transplantation (Excluded Material) (Bailiwick of Guernsey) Ordinance, 2022 excludes the following material from deemed consent donation:

- The whole of, or a visibly recognisable part of, any of the following body parts -
  - (i) brain,

a)

- (ii) spinal cord,
- face (other than the eyes),
- (iv) arm,
- (v) hand,
- (vi) leg, and
- (vii) foot,
- b) any other human tissue (including skin or internal tissue), but only if it is being removed for the purpose of the transplantation of material described in subparagraph (a),
- c) an embryo that is inside the body of a person, and
- ovary, uterus, penis, testicle, foetus, placenta and umbilical cord. d)

<sup>&</sup>quot;Internal tissue" includes, but is not limited to, bone, muscle, nervous tissue, arteries and tendons.

# Appendix 2 – Qualifying relationships

For the purposes of express consent, these are qualifying relationships:

- 1. Spouse or civil partner of the potential donor;
- 2. Parent or child of the potential donor;
- 3. Brother or sister of the potential donor;
- 4. Grandparent or grandchild of the potential donor;
- 5. Aunt or uncle of the potential donor;
- 6. Niece or nephew of the potential donor;
- 7. Stepfather or stepmother of the potential donor;
- 8. Long standing friend of the potential donor;
- 9. The potential donor is living in the care of the person concerned pursuant to an order made under section 14 of the Children (Guernsey and Alderney) Law, 2008 or section 13 of the Children (Sark) Law, 2016, as the case may be; and
- 10. Guardian of the potential donor under any custom or rule of law.

Qualifying relationships include those that are half blood.

The list of qualifying relationships above is ranked in descending order. Relationships in the same position on the list (for example, parent and child) are of equal ranking.

# Appendix 3 – Express consent for adults (Table 1) and children (Table 2)

Table 1: Express consent for adults

Express consent for ADULTS		
	Case	Person giving express consent
1.	The adult is alive.	That adult.
2.	The adult has died and a decision of the adult as to consent to the regulated activity was in effect immediately before the adult's death.	That adult.
3.	The adult has died, case 2 does not apply, the adult had appointed a person under section 9 to deal with the issue of express consent and the appointed person is available to give express consent under the appointment.	The appointed person.
4.	The adult has died, case 2 does not apply and the adult had appointed a person under section 9 to deal with the issue of express consent but the appointed person is unavailable to give express consent under the appointment.	Any person who stood in a qualifying relationship to the adult immediately before the adult's death.
5.	The adult has died and none of cases 2, 3 or 4 applies in relation to that adult.	Any person who stood in a qualifying relationship to the adult immediately before the adult's death.

Table 2: Express consent for children

Express consent for CHILDREN		
	Case	Person by whom the express consent is given
1.	The child is alive, no decision of the child as to consent to the regulated activity is in effect, and either the child is not competent to deal with the issue of express consent or is competent to deal with the issue but fails to do so.	Any person who has parental responsibility for the child.
2.	The child is alive and case 1 does not apply.	That child.
3.	The child has died and a decision of the child as to consent to the regulated activity was in effect immediately before that child's death.	That child.
4.	The child has died, case 3 does not apply, the child had appointed a person under	The appointed person.

		·
	section 9 to deal with the issue of	
	express consent and the appointed	
	person is available to give express	
	consent under the appointment.	
5.	The child has died, case 3 does not apply	Any person who had parental
	and the child had appointed a person	responsibility for the child immediately
	under section 9 to deal with the issue of	before the child's death or, where no
	express consent but the appointed	such person exists, the consent of any
	person is unavailable to give express	person who stood in a qualifying
	consent under the appointment.	relationship to that child immediately
		before that child's death.
6.	The child has died and none of cases 3, 4	Any person who had parental
	or 5 applies in relation to that child.	responsibility for the child immediately
		before the child's death or, where no
		such person exists, the consent of any
		person who stood in a qualifying
		relationship to that child immediately
		before that child's death.

# Appendix 4 – exemptions to deemed consent

Section 7 (1) of <u>The Human Tissue and Transplantation (Bailiwick of Guernsey) Law, 2020</u> sets out that consent is deemed to be given for a deceased adult <u>unless</u> –

- (a) the human tissue is or contains excluded material,
- (b) the case falls within the description of case 2, 3 or 4 of Table 1 of Appendix 3 (express consent for adults) of this Code,
- (c) a decision of the adult not to consent to transplantation activity is in effect,
- (d) the adult is an excepted adult,
- (e) the adult would not have consented to the transplantation activity, or
- (f) proceeding with the transplantation activity would lead to severe distress in or severe conflict amongst persons who stood in a qualifying relationship to the adult immediately before death.

# Glossary

Term	Definition
Appropriate consent	This is broadly either the consent of the person concerned, their appointed person, that of a person in a qualifying relationship to them immediately before they died or (in the absence of any of these) deemed consent.
	In the case of a potential donor aged under 18 years, it could be the consent of a person with parental responsibility over the child.
Best interests	An assessment of a person's best interests takes into account not only the risks and benefits of a proposed intervention, but also its wider emotional, psychological and social aspects.
Cells	Individual human cells or a collection of human cells that are not bound by any form of connective tissue.
Deemed consent	In the absence of express consent and where there is no record of a person's decision on organ donation, their consent will be deemed unless information is provided that the person would not have wanted to be an organ donor.
	Exemptions to deemed consent are set out in Appendix 4.
Diagnosis	The identification of the nature of an illness or other problem.
Donation	The act of giving human tissue, cells, organs or part organs for a specified purpose, either during life or after death.
Donation after Brainstem Death (DBD)	A form of organ donation in circumstances where a patient, whose death has been diagnosed and confirmed using neurological criteria, continues to be ventilated. This keeps the heart beating and blood circulating after death, until after donation takes place.
Donation after circulatory death (DCD)	A form of organ donation in circumstances where the deceased donor was not ventilated at the time of death. Donation therefore occurs after death is diagnosed and confirmed using cardio-respiratory criteria.
	This is described as controlled when treatment has been actively withdrawn within a hospital setting or uncontrolled where a patient has experienced an unexpected cardiac arrest from which they cannot be resuscitated.
Excepted adult	An adult who had not been ordinarily resident in the Bailiwick for a period of at least 12 months immediately before their death; or who lacked the capacity to understand the notion of deemed consent for a sufficient period before their death.
Excluded material	Material excluded from deemed consent donation. See Appendix 1.
Express consent	Express consent is consent to donation given by the potential

	donor, their appointed person, or someone who stands in a qualifying relationship.
	In the case of a potential donor aged under 18 years, the consent of a person with parental responsibility over the child is also considered express consent.
Family	Family should be taken to mean people involved in the end of life care of an individual, who may be able to provide information about them and their decision with regard to organ and tissue donation. Family encompasses those in a qualifying relationship to the deceased person immediately before death and other family members and close friends.
Human Tissue	Defined by the Organ Donation Legislation as material which consists of or includes human cells, but excludes live human gametes (other than eggs in the process of fertilisation), embryos outside the human body and hair or nails from the body of a living person
Minimum steps	The Organ Donation Legislation allows for the minimum steps necessary to be taken to preserve organs in a state which allows successful donation, using the least invasive procedure such as cold perfusion and intraperitoneal cooling.
Appointed person	A person appointed by an individual to represent them after their death for the purposes of activities under the Organ Donation Legislation for which consent is required. An appointed person may be entitled to consent to, or refuse to consent to, the removal, storage and use of the body or tissue for the purpose of transplantation or for a teaching, research or therapeutic purpose.
	In relation to organ donation in England, the appointed person is known as a <i>nominated representative</i> .
Organ	This refers to a differentiated part of the human body, formed by different tissues, that maintains its structure, vascularisation and capacity to develop physiological functions with a significant level of autonomy. Part of an organ is also considered to be an organ if its function is to be used for the same purpose as the entire organ in the human body, maintaining the requirement of structure and vascularisation.
NHS Organ Donor Register (ODR)	A confidential, computerised national database managed by NHS Blood and Transplant (NHSBT), which holds details of people who have signed up to become organ donors in the event of their death. It also holds details of people who have stated they do not want to donate their organs after their death. The register is used after a person has died to help establish whether they wanted to donate and if so, which organs or tissue.
Parental responsibility	A person who has parental responsibility will usually, but not always, be the child's parent. The category of persons with parental

	responsibility is set out in the Children (Guernsey and Alderney) Law, 2008 or the Children (Sark) Law, 2016.
Perfusion	A method of treating organs to preserve them before transplantation. In the deceased donor this will take place after death.
Post-mortem examination	Also called an autopsy, a post-mortem is an examination of the body after death. Post-mortems are performed if the cause of death is not known or if there are any unusual circumstances. Information obtained from a post-mortem often helps bereaved families understand what happened to their loved one as well as helping
Potential donor	doctors learn about how diseases can affect the body.  Every human source, whether living or deceased, of tissue, cells, organs or part organs.
Practitioner	A doctor or nurse providing end of life care and/or working in the medical speciality of organ donation.
Qualifying relationship	The relationship to the deceased of a person/s who can give consent for the removal, storage and use of organs and tissue from the deceased person's body for the purpose of transplantation or for a teaching, research or therapeutic purpose. In certain circumstances, or provide information that would lead a reasonable person to conclude that a potential donor would not have consented in circumstances where consent could be deemed. Those that are in a qualifying relationship are set out at Appendix 2.
Reasonable	A reasonable person is one who exercises an ordinary degree of care,
Research	skill, and judgement in particular circumstances.  A study which addresses clearly defined questions, aims and objectives in order to discover and interpret new information or reach new understanding of the structure, function and disorders of the human body. Research attempts to derive new knowledge and includes studies that aim to generate hypotheses, as well as studies that aim to test them or develop practical applications or new knowledge.
Regulated activity	Under the Organ Donation Legislation, consent must be obtained to remove human tissue from the body of a deceased person or remove the body of a deceased person for a teaching, research or therapeutic purpose (a 'regulated activity').
	Other regulated activities include storing the body of a deceased person for the purpose of transplantation and carrying out tests and investigations to determine whether human tissue is suitable for the purpose of transplantation.
Sufficient period	This refers to a sufficiently long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed due to the lack of capacity of the donor before death. In the Bailiwick, the Organ Donation Legislation sets out this period of time to be all or the majority of the 12 months immediately prior to death.

	The majority of a 12 month period is 6 (calendar) months plus 1 day.
Specialist	A senior nurse who is the focal point of contact for organ and tissue
Nurse for Organ	donation within the Hospital. The role encompasses different aspects
Donation	which all come together in the identification and referral of potential
(SNOD)/Speciali	organ and tissue donors. It is recognised as best practice to have a
st Requester	SNOD/SR/SNTD involved in the donation conversation.
(SR)/Specialist	
Nurse in Tissue	The SNOD/SR/SNTD is the expert in both donation conversation and
Donation	the legislation and is considered to be the 'authorised person' for the
(SNTD)	purpose of the Organ Donation Legislation. For ease of reference,
	these three roles are represented as 'SNOD' throughout this
	document.
Tissue	Any and all constituent part/s of the human body formed by cells
Transplantation	An implant of an organ or part organ, tissue or cells either from and
	into the same body or from one person to another.
Valid consent	Consent which has been given voluntarily, by an appropriately
	informed person who has the capacity to agree to the activity in
	question.