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Health and Community Services
Consent to Care and Treatment

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Description	To set out the standards and procedures in HCS which aim to ensure that care practitioners are able to meet the requirements of the law and best practice in relation to the consent process.
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CONTENTS LIST:

1. INTRODUCTION

1.1 Rationale

High quality care should be safe and provided in a way that ensures the best possible experience of care. Opportunities must be provided to discuss individual health beliefs, concerns and preferences to inform care and support the right to choose, accept or decline treatment. All Health and Community Services (HCS) service users must be treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.

Case law (common law) has established that touching a patient without valid consent may constitute the civil or criminal offence of battery. An inadequate consent process also damages the care practitioner-patient relationship. Furthermore, if care practitioners fail to obtain valid consent and the patient subsequently suffers harm as a result of the treatment, this may be a factor in a claim of negligence.

The Supreme Court judgment in the case of *Montgomery* v *Lanarkshire Health Board* [2015] UKSC 11[1], represents a landmark decision for the care practitioner-patient relationship and the process of informed consent. Reasonable steps must be taken to ensure that patients are aware of any risks that are material to them and should inform their patients of alternative treatments, including the option of no treatment. This has since been reinforced in *Webster* (A Child) v. *Burton Hospitals NHS Foundation Trust* [2017] EWCA Civ 62[2]: the Courts have indicated that they will take a wide range of factors into consideration, including the person's education and conduct through the relevant treatment when considering *Montgomery*. Doctors are now under a duty to understand the particular and personal concerns of their patients.

The *Bolam*[31] test no longer applies to the issue of consent. The law treats patients, so far as possible, as persons capable of understanding that medical treatment is uncertain of success and may involve risks, of accepting responsibility for risks affecting their lives and of living with the consequences of their choices[1].

The law requires a doctor to take '*reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment and of any reasonable alternative or variant treatment'*[1]. Material risk is defined in law as either a risk to which *a reasonable person in the patient's position would be likely to attach significance*, or a risk that a doctor knows – or should reasonably know – would be deemed of significance by this particular patient. Failure by HCS employees to adhere to this principle could expose HCS to legal action due to the actions of employees.

This policy sets out the standards and procedures in HCS which aim to ensure that care practitioners are able to comply with the relevant law and best practice guidelines issued by regulatory bodies relating to consent.

[1] According to *Bolam,* 'a doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art'. In *Sidaway* v *Board of Governors of Bethlehem Royal Hospital,* the *Bolam* standard was applied to the information given as well as the treatment chosen and the method of carrying out.

In cases where there is conflict, guidance should be sought from line managers in the first instance, who in turn can escalate according to the context of the situation. Guidance can also be sought from the appropriate professional and regulatory bodies.

1.2 Scope (including other Government of Jersey Bodies)

For the purpose of this document, consent refers to the rights of patients to decide what, if any, care they are to receive and the duty of the care practitioner to ensure that patients have given their permission prior to any care-giving, treatment, examination or intervention.

This policy aims to ensure that all employees working within HCS who have direct contact with patients comply with the required consent process.

Whilst this document has been primarily written for HCS employees, it will be relevant to employees working within other Government of Jersey bodies including Children, Young People, Education and Skills and Justice and Home Affairs.

2. LEGISLATIVE FRAMEWORK

Whilst there is no legislation in Jersey which sets out the principles of consent, English case law would be strongly considered in its absence. English law also forms the basis for much of the regulatory body guidance. Therefore, for the purposes of consent, HCS looks to best practice and law from England.

However, care practitioners must be aware of the areas in which Jersey law differs from English law. In such instances, Jersey law must be followed.

European Convention on Human Rights (ECHR)

In Jersey, the Human Rights (Jersey) Law 2000 (enacted 2006) gives effect to the rights enshrined in the ECHR. All public authorities are required to act in accordance with the rights set out in this law. The main articles that are likely to be relevant are;

- Article 2 The protection of the right to life.
- Article 3 The prohibition of torture and inhumane or degrading treatment or punishment.
- Article 5 The right to liberty and security.
- Article 8 The right to respect for private and family life.
- Article 9 Freedom of thought, conscience and religion.
- Article 14 The prohibition of discrimination in the enjoyment of Convention rights.

Mental Health Act (1983)

When references to the Mental Health Act 1983 are made, the relevant provisions of the Mental Health Law (Jersey) (MHL) 2016 should be read.

Mental Capacity Act (2005)

When references to the Mental Capacity Act (2005) are made, the relevant provisions of the Capacity and Self-Determination Law (Jersey) (CSDL) 2016 should be read.

Family Law Reform Act (1987)

Under this Act, people aged 16-17yrs are entitled to consent to their own treatment. Under Consent to Medical Treatment Law (Jersey) 1973, people aged 16-17yrs are also entitled to consent to their own medical treatment in Jersey.

Children's Act (1989)

In England, this Act sets out those people who may have parental responsibility for a child. In Jersey, the equivalent legislation is the Children (Jersey) Law 2002.

3. GENERAL PRINCIPLES OF CONSENT

Within this document, the terms 'must and 'should' are used in the following ways:

- 'Must' is used for an overriding duty or principle.
- 'Should' is used where the duty or principle will not apply in all situations or circumstances, or where there are factors outside your control that affects whether or how you can follow this guidance.

3.1 Requirements for valid consent

For consent to be valid, it must be:

- Given by a person with capacity to consent or refuse consent to the intervention in question, or any other legal decision maker,

- Given voluntarily and freely, without pressure or undue influence being exerted on the patient either to accept or refuse treatment and,

- Based on appropriate information and understood (informed).

Acquiescence where the patient does not know what the intervention involves, is not consent[8].

3.2 Does the person have capacity to consent?

To determine if a person has capacity to make particular decisions, a single test must be applied: this requires asking if at the material time the person is unable to make their own decision in relation to the matter because they suffer from an impairment or a disturbance in the functioning of his or her mind or brain.

A person is unable to make a decision if they cannot satisfy one or more of the below:

a. Understand information relevant to that decision.
b. Retain the information for a period, however short, which is sufficient to make the decision.
c. Use or weigh the information in making the decision.
d. Communicate the decision.

Capacity is time and decision specific; a person may have the capacity to consent to simple care and treatment decisions but not complex decisions.

When assessing capacity, the core principles must be followed:

Principle 1

All persons (16+) are assumed to have capacity unless it is established that they lack capacity.

Principle 2

A person is not to be treated as unable to make a decision unless all practical steps have been taken to help them make a decision.

Principle 3

A person is not to be treated as unable to make a decision merely because they make an unwise decision.

Principle 4

Anything done for or on behalf of a person who lacks capacity must be done in their best interests.

Principle 5

The purpose for which an act is done or a decision is made on behalf of a person who lacks capacity should be achieved in ways that are least restrictive to the person concerned.

Care practitioners have a duty to support decision-making and should take all reasonable steps in the circumstances to facilitate communication with the person; including using an independent capacity advocate (ICA), learning disability specialists, speech and language therapists, interpreters or communication aids as appropriate and ensuring that the patient feels at ease. In particular, careful consideration should be given to the way in which information is explained or presented to the patient. Where appropriate, those who know the patient well, including their family, carers and staff from professional or voluntary support services may be able to advise on the best way to communicate with the person.

Pain, fear, panic, fatigue and medication can impact upon a person's capacity. All reasonable and practicable steps should be taken to alleviate these symptoms. If this cannot be done, a best interest approach must be followed. For example, a person may be still be experiencing the effects of night sedation during the morning period with a subsequent effect upon capacity, therefore discussions should take place in the afternoon. People with Alzheimer's and dementia may also experience increased confusion, anxiety and agitation later on the day which could affect capacity (sundowning syndrome)[9].

For more detailed guidance on capacity, please refer directly to the Capacity and Self-Determination (Jersey) Law 2016 and the Capacity and Self-Determination (Jersey) Law 2016 Code of Practice.

3.3 Is consent given voluntarily?

It is a principle of English common law that consent must be given voluntarily and freely, without pressure or undue influence being exerted upon the person to accept or refuse treatment[2].

Care practitioners must be alert to the possibility that such pressure can come from partners, family members, religious groups, friends, associates and without intention, by care practitioners themselves. Where appropriate, arrangements should be made to see the person on their own to establish that the decision made is genuinely their own.

When people are seen and treated in environments where involuntary detention is an issue (police cell, prison, mental health hospitals), there is a potential for treatment offers to be perceived coercively, whether or not this is the case. Coercion invalidates consent so extra care must be taken to ensure that the person makes a decision freely[8].

3.4 Has the patient received sufficient information?

Once the first two requirements have been satisfied, the last requirement for consent to be valid is that the person needs to understand the nature and purpose of the procedure.

Care practitioners must take reasonable steps to ensure that patients are aware of any risks that are material to them and should inform their patients of alternative treatments, including the option of no treatment. Material risk is defined in law as either a risk to which a reasonable person in the patients position would be likely to attach significance, or a risk that a care practitioner knows – or should reasonably know – would be deemed of significance by this particular patient[1].

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[2] *Re T (Adult) [1992] 4 All ER 649*
A pregnant woman was injured in a car accident and developed complications that required blood transfusions. She did not indicate on admission that she was opposed to receiving blood but after spending time with her mother, a practicing Jehovah's Witness, she decided to refuse the treatment. The Court of Appeal decided that she had been pressurized by her mother and that her ability to make a decision was further impaired by the drugs with which she was being treated. The Court allowed the blood transfusions to proceed.

Assessing the significance of a risk is fact-sensitive and cannot be reduced to percentages. What might constitute a material risk to a particular patient does not depend on its size. The *Montgomery* ruling states that '*the assessment of whether a risk is material cannot be reduced to percentages. The significance of a given risk is likely to reflect a variety of factors besides its magnitude: for example*, *the nature of the risk, the effect which its occurrence would have upon the life of the patient, the importance to the patient of the benefits sought to be achieved by the treatment, the alternatives available, and the risks involved in those alternatives. The assessment is therefore fact-sensitive, and sensitive also to the characteristics of the patient'*[1].

In practical terms, care practitioners have to consider[10];

1. Does the person know about the material risks of the proposed treatment?

    - What sorts of risk would a reasonable person in the person's circumstances want to know?
    - What sort of risks would this particular person want to know?

2. Does the person know about reasonable alternatives to this treatment?

3. Has reasonable care been taken to ensure that the person actually understands all this?

4. Do any of the exceptions to the duty to disclose apply here?

    - Person states that he / she does not want to know the risks.
    - Care practitioners may reasonably consider that disclosure would cause the person serious harm (beyond merely causing distress).
    - Where urgent treatment is needed.

5. Has the consent process been fully and properly documented; the discussion and reference to any literature provided?

Pre-*Montgomery,* the General Medical Council (GMC)[11] [3]provided guidance on the type of information that patients may need to know before making a decision and recommends that doctors should do their best to find out about patients individuals needs and priorities when providing information about treatment options.

Where the patient makes clear that they do not wish to be given this level of information, this should be clearly documented and respected.

The reality facing care practitioners in current practice is that time pressures can leave little opportunity to discuss at length the diagnoses or available treatment options. However, this does not change the fundamental legal requirement that surgeons and doctors allocate sufficient time for a discussion that will allow them to understand the individual patient and their needs[26]. According to the judges in *Montgomery, 'even*

[3] GMC is currently consulting on its consent guidance: new guidance should be available late 2018.

those who have less skill or inclination for communication, or are more hurried, are obliged to pause and engage in the discussion which the law requires'.

For examples of how the law has been applied post-*Montgomery*, please refer to the relevant case law section (Appendix 1).

A signature on a consent form or a pre-printed proforma (procedure specific consent form) does not remove the requirement for this discussion to take place or the requirement for the full and proper documentation of this discussion.

3.5 Provision of patient information

The provision of information is central to the consent process. Patients require comprehensive and comprehensible information about their condition before they are in a position to make a decision about treatment. This must include the risks and benefits of all possible treatments, the option of doing nothing and comparative risks with other procedures. Individuals also need to know whether additional procedures are likely to be necessary as part of the procedure, for example, blood transfusion.

Discussions with patients may need to be supported using written material, visual or other aids. Referring to particular websites, advocacy services, expert patient programmes or support groups may prompt the patient to ask further questions to more fully understand the treatment being proposed. However, any patient information must always be accurate, up-to-date and reflect best practice. The use of patient information leaflets is considered to be an effective method to provide patients with the information they need to make an informed decision. Patients are able to review the information after their consultation.

However, the use of alternatives sources of information must not be regarded as providing the patient with all of the necessary information for the purpose of obtaining consent; this does not satisfy the obligations of care practitioners. Obtaining valid consent is a process which involves effective communication and dialogue.

Any information given to patients must include details about how to contact the appropriate care team to ascertain further information should it be required. Where possible, it is much quicker and easier for the patient to contact a member of their care team by phone, rather than to wait for another appointment.

HCS recognises it is sometimes difficult because of time pressures and limited resources available, to give patients as much information or support in making decisions as we would like. Consideration should be given to the role that other services and other members of the care team might play, for example, pre-admission clinic, advanced nurse practitioners, specialist nurses, specialist physiotherapists and occupational therapists. However, the responsibility for information provision lies with the practitioner seeking consent.

In addition to providing information, care must be taken to ensure that patients have understood the information. This is particularly important for patients admitted on the day of a procedure where the opportunity for prolonged discussion is limited. If a

patient has any queries or concerns then they must be given time to consider any additional information. Waiting until the day of an elective procedure is too late for the information genuinely to affect the patient's choice, therefore the consenting discussion should start in the pre-admission period.

For an overview of the process that aims to optimise the time available for providing the required information and discussing options for treatment to facilitate the patient decision, please see Appendix 2.

Remember, acquiescence, where the patient does not know what the intervention involves, is not valid consent.

3.6 Communication

To support decision-making and facilitate communication, interpreters or communication aids must be used as appropriate. Accurate exchanges of information are paramount and it is the aim of HCS to ensure that a range of Language Service Assistants (LSA), interpreters and translators are provided for those people for whom English is not their first language or who may have a disability where communication is impaired visually or audibly[12].

Written information is available for a number of topics in languages commonly read by local patients. Braille and large-print versions are available on request for patients with impaired vision. Interpreters and readers are available for those patients unable to read the written information provided.

For more detailed guidance, please see HCS interpreting policy & procedure.

Other factors to consider in relation to communication include:

- Poor numerical literacy hindering quantification of risk.
- Medical illiteracy leading to lack of understanding of medical terminology.
- Using simple language and avoiding jargon: use of pictures / objects may be useful.
- Different preferences for types of learning, (e.g.) visual, auditory.
- Ensuring the patient feels at ease.
- Accommodate a patient's wishes to have another person involved in discussions to support the understanding of information and to help in making a decision, but remember the issue of coercion or duress.
- Where appropriate, those who know the patient well, including their family, carers and staff from professional or voluntary support services, may be able to advise on the best ways to communicate with the person.
- Patients with additional needs, such as those with disabilities, must be given the time and support they require to make a decision.

3.7 Who should seek consent?

The care practitioner providing the care or treatment is responsible for ensuring that the person has given valid consent before beginning the treatment. This is the individual who will be deemed responsible in law if the process of consent is challenged later.

3.8 Care practitioners delegating consent

GMC[11] guidance states that the task of seeking consent may be delegated to another person, provided that such a person;

- Is suitably trained and qualified,
- Has sufficient knowledge of the proposed investigation or treatment and understands the risks involved,
- Understands and agrees to act in accordance with this HCS policy and the relevant regulatory body guidance.

If the task of seeking consent is delegated, it is the responsibility of the care practitioner performing the procedure to ensure that the patient has given valid consent before the procedure is started.

This can include;

- specialist nurses
- advanced nurse practitioners
- specialist physiotherapists
- specialist occupational therapists

Inappropriate delegation invalidates the consent process. Regular audit will be undertaken to identify any such instances.

If a care practitioner seeks consent for a procedure they are not competent to perform themselves, a Datix form must be completed. Additionally anyone who feels pressurised or is inappropriately asked to seek consent, should contact the Head of Quality and Safety immediately.

The assurance framework around delegated consent is under development at the time of publication of this policy. Once complete, the framework and the accompanying process will be appended to this policy.

3.9 When should consent be sought?

Consent should be a process rather than a one-off event; information giving, discussion and decision-making. This process may take place at one time (single stage) or over a series of appointments and discussions, depending upon the complexity of what is proposed and the urgency of the patient's condition.

For both major and minor interventions, it is good practice where possible to seek the patient's consent to the proposed procedure well in advance, when there is time to

respond to the patient's questions and provide adequate information. However, this may not always be possible.

Single stage process

In certain cases, it will be appropriate for a care practitioner to begin a procedure immediately after discussing it. As long as the elements for valid consent are satisfied, the care practitioner may proceed. However, if the proposed procedure is complex, it is unlikely that valid consent could be properly accomplished in a single stage process, so health care professionals must take into account whether the patient has had adequate time to think about the information in order to reach their decision.

Similarly, if a proposed procedure involves risks that the patient would attach significance to; care practitioners must take into consideration whether the patient has had sufficient time to consider the information necessary for them to reach a decision, proceeding only if it is clear that the patient understands and gives consent.

Multi-stage process

In other cases, treatment options may be discussed in advance of the proposed procedure. This may be on one occasion (out-patient appointment), or it might be over a series of consultations with a number of different care practitioners; thus, the consent process has a number of stages. The medical records must be used as a means of documenting all these stages.

Where written consent is sought, patients should be familiar with the content of the consent form before they arrive for the procedure and should have been given a copy of the page documenting the decision-making process. Once a patient confirms that they wish to go ahead, they may be invited to sign the consent form and / or entry in the medical record.

Immediately before the procedure, it is necessary to ensure that the patient's condition has not changed, that they do not have any further concerns and still give their consent. If any queries or concerns are raised, they must be given time to consider any additional information.

Throughout the consent process, the patient must feel that it would have always been possible for them to refuse consent or change their mind. If a person is not asked to give consent until just before the procedure is due to start, at a time when they may be feeling vulnerable and do not have the opportunity to ask questions, there may be real doubts as to its validity[4].

For a course of treatments, consent to continue should be confirmed before each individual component, with any changes to the risks, benefits or alternatives fully discussed and documented.

[4] In *Kathleen Jones* v. *Royal Devon and Exeter NHS Foundation Trust* [2015], Mrs Jones was informed by a nurse on the day of the operation, just prior to going into theatre, that her choice of surgeon would not be performing the surgery. A range of factors were considered by the Court in its ruling, including that it was too late for her to be expected to exercise informed choice when she was only told moments before the operation.

3.10 Form of consent

The validity of consent does not depend on the form in which it is given. A signed consent form serves as evidence of consent; if the elements of capacity, voluntariness and appropriate information have not been satisfied, a signature on a form will not make the consent valid.

Consent may be expressed non-verbally or verbally. An example of non-verbal consent would be where a patient, after receiving the appropriate information, holds out an arm for their blood pressure to be taken. However, the patient must have understood what examination or treatment is intended, why, and the consequences, for such consent to be valid.

In the case of minor or routine investigations or treatment, if the care practitioner is satisfied that the patient understands what is proposed and why, it is usually enough to obtain verbal / non-verbal consent[11].

Whilst the process of obtaining consent is a legal requirement, the completion of a consent form is not. GMC[11] guidance states that clinicians should have documented written consent from a patient if:

- The investigation or treatment is complex or involves significant risks or risks which the patient would attach significance to.
- There may be significant consequences for the patients' employment and / or social and / or personal life.
- Providing clinical care is not the primary purpose of the investigation or treatment (for example, research or educational purposes).
- The treatment is part of a research programme or is an innovative treatment designed specifically for their benefit.

It is essential to clearly document a patient's agreement or refusal and the discussion(s) which led to it. This may be done through the use of a consent form (with further detail in the patient's notes if necessary) or through documenting directly in the patients notes. Irrespective of whether consent is expressed verbally, non-verbally or counter-signed, the key elements of the discussion with the patient which must be recorded include[11]:

- The information discussed.
- Any specific requests by the patient.
- Any written, visual or audio information given to the patient (ideally with a copy appended to the records, if not, a record of the version number).
- Any external resources patient directed to, for example, websites, organisations.
- Details of any decisions made.

If there is any dispute over whether valid consent was obtained, the key issue will not be whether the patient signed a form or not, but whether they were given all the information they needed to make a considered decision. It is therefore important to document the essential elements of discussions with the patient, using the consent principles as a framework.

3.11 Consent form

Only HCS approved consent forms must be used.

3.12 Procedure specific consent form

With the exception of those forms already in use (urology, ophthalmology, cardiology and oncology), no other procedure-specific consent forms are to be introduced within HCS.

The procedure specific consent forms already in use must not be used as a checklist to be ticked off without recording further detail. Consider the individual circumstances of each patient and explore what risks are of significance to them personally. Therefore, in conjunction with the use of the procedure specific consent form, there must be clear additional documentation of the discussion which led to the decision within the patient's record.

3.13 Duration of consent

When a person gives valid consent, that consent remains valid unless it is withdrawn by the patient. However, it is good practice to confirm that the patient who has given consent still wishes the intervention to proceed, even if no new information needs to be provided or further questions answered. GMC[11] guidance states that an appropriate care practitioner should reconfirm consent, particularly if;

- A significant amount of time has passed since the initial decision has been made.
- There have been any material changes in the condition of the patient.
- New information becomes available regarding the proposed treatment or alternative treatment options.

If the patient's condition has changed significantly in-between times, it is necessary to seek consent again on the basis that the likely benefits and / or risks may also have changed.

3.14 Qualified (restricted) consent

For religious or other personal reasons, some patients may qualify (restrict) their consent to treatment by refusing specific aspects of that treatment. Jehovah's Witnesses, for example, may differ in their acceptability of blood and blood component transfusions.

If a patient gives consent with restriction(s), the precise nature of the restriction(s) that has been imposed by the patient should be clearly documented in the hospital notes. The records should reflect that the patient has been informed of the likely

consequences of this decision, together with the reasons why such a treatment was proposed in the first place.

Qualified (restricted) consent does not remove a patient's right to reasonable and proper care, including provision of all other forms of treatment that are appropriate in the circumstances. If a care practitioner does not feel able to provide proper care consistent with the patient's wishes, then the care practitioner can refuse to treat the patient, provided that no additional harm is likely to result from that refusal and reasonable attempts are made to find a different care practitioner who is willing to treat the patient.

3.15 When consent is refused

If the process of seeking consent is to be meaningful, refusal must be one of the patient's options.

If a person with capacity makes a voluntary and appropriately informed decision to refuse treatment (contemporaneously or in advance), even if the care practitioner thinks this decision is wrong or irrational, this decision must be respected, except in circumstances defined by the Mental Health (Jersey) Law 2016[5] (see section 4.28).

If after discussion of all possible treatment options, a person refuses all treatment, this must be escalated to the consultant with overall responsibility and the facts should be clearly documented in the patient's notes.

If the patient has signed a consent form but subsequently changes their mind, this should be noted on the form and request that the patient countersigns this.

Where a patient has refused a particular intervention, continue to any other provide appropriate care to which the patient has consented and that the patient is made aware that they are free to change their mind and accept treatment if they later wish to do so. Where delay may affect their treatment choices, patients must be advised accordingly.

3.16 Advance decisions to refuse treatment

A person may have made an ADRT in anticipation of a time where they lack capacity or are unable to communicate a decision. A valid and applicable ADRT has the same force as a contemporaneous decision to refuse treatment.

For more detailed guidance on ADRT, please refer directly to HCS ADRT policy.

3.17 Withdrawal of consent

A person with capacity is entitled to withdraw consent at any time, including during treatment. A signed consent form is not a binding contract.

[5] The Mental Health (Jersey) Law 1969 applies to those who may have, or are diagnosed as having a mental disorder and defines the circumstances in which patients can be admitted, detained and treated in hospital without consent.

Where a patient does withdraw consent during treatment, it is good practice to stop the procedure if possible, establish the concerns of the patient and explain the consequences of not completing the procedure. All reasonable and practicable steps should be taken to alleviate any symptoms of pain, fear or anxiety. If stopping during the procedure at that point would put the life of the patient at immediate risk or cause significant harm, continue until that risk no longer exists.

3.18 Consent to anaesthesia

The Anaesthetic Association of Great Britain and Ireland (AAGBI)[13] have produced guidelines in response to the changes in the ethical and legal context around delivering healthcare. In summary:

1. Information about anaesthesia and its associated risks should be provided to patients as early as possible, preferably in the form of an evidence based online resource or leaflet that the patient can keep for future reference. Those undergoing elective surgery should be provided with information before admission, preferably at pre-assessment or at the time of booking. However, the duty remains on the anaesthetist to ensure that the information is understood. This is particularly important for patients admitted on the day of surgery where the opportunity for prolonged discussion is limited.

2. Immediately before the induction of anaesthesia, (in the anaesthetic room), is not an acceptable time to provide elective patients with new information. Verification that consent has been given should be done again in the anaesthetic room, but this is not the place where risks, alternatives and additional procedures are discussed.

3. The amount and nature of information that should be provided to the patient should be determined by the question, 'What would this particular patient regard as relevant when coming to a decision about which of the available options to accept?'

4. At the end of an explanation about a procedure, patients should be asked whether they have any questions: any such questions should be addressed fully and details recorded.

5. Anaesthetists should record details of the elements of a discussion in the patient record; noting the risks, benefits and reasonable alternatives, including the option of no treatment.

6. A separate consent form signed by the patient is not required for anaesthetic procedures that are done to facilitate another treatment. However, if the anaesthetic procedure is the primary therapeutic intervention, it is a good practice that a consent form is completed and signed by the patient.

7. Consent is an on-going process not a single event and may require repeated discussion and / or confirmation with documentation at every stage.

8. For a course of treatment, consent to continue should be confirmed and documented before each individual component and any changes to risk, benefits and alternatives fully discussed.

9. If patients insist that they do not want to know about the risks of a procedure (including anaesthesia), the consequences of this should be explained. This discussion should be recorded in writing and the patients given the opportunity to change their mind. Patients should understand that there may be risks but should not have a detailed explanation forced upon them if unwilling.

In essence, the anaesthetist must be satisfied that patients have been given sufficient time to come to a considered view after they have been provided with relevant information about their treatment and have had the opportunity for adequate discussion, even if admitted on the same day of surgery. The time required for this will depend on the patient and the nature of the procedure.

3.19 Additional procedures

Where reasonable, any foreseeable additional procedures must be fully documented following discussion. The foreseeable additional procedures are essential information that any service-user requires to reach a decision about whether to proceed. It is never acceptable to document the procedure followed by '+/- proceed'.

However, during a procedure, it may become evident that the person would benefit from an additional procedure that was not within the scope of the original consent. If it would be unreasonable to delay the procedure until the person regains consciousness, it may be justified on the grounds that it is in the patient's best interests.

If a person has refused certain procedures before the anaesthetic, then this must be respected if the refusal is applicable to the circumstances. GMC[11] guidance states that it is good practice to seek the views of the patient on possible additional procedures when seeking consent for the intended procedure.

3.20 Consent to blood transfusion

Blood or blood component transfusion is a transplant. Therefore, valid consent is required prior to commencing blood or blood component transfusion. If the elements of capacity, voluntariness and appropriate information have not been satisfied, a tick on a consent form will not make the consent valid without recording further detail of the discussion regarding blood transfusion, the risks and benefits and the alternatives available.

The key elements of the discussion with the patient which must be recorded in the patients' medical notes or on a consent form, include:

- The information discussed.
- Any specific requests by the patient.

- Any written, visual or audio information given to the patient (ideally with a copy appended to the records, if not, a record of version number).
- Any external resources patient directed to (e.g.) websites, organisations.
- Details of any decisions made.

For religious or other personal reasons, some patients may qualify their consent to treatment by refusing specific aspects of that treatment. Jehovah's Witnesses, for example, may differ in their acceptability of blood and blood component transfusions.

For further guidance please see HCS blood transfusion policy.

3.21 Consent for cosmetic surgery

The general principles for obtaining valid consent apply when seeking consent for a cosmetic procedure; it is the process of providing the information that enables the patient to make a decision to undergo surgery, not the signing of a form. In addition, GMC[14] guidance highlights key points which are important to protect patients' interests in relation to cosmetic interventions.

Responsibility for seeking consent for cosmetic interventions,

- lies with the practitioner who will be carrying out the intervention.
- must not be delegated.
- must be in writing.

Consent should be obtained in a two-stage process with a cooling-off period of at least two weeks between the stages to allow the patient to reflect on the decision. If this is not possible, the reason(s) must be recorded in the patient's notes. Information on the procedure should be received at a different time to the signing of the consent form. The right of patients to change their mind at any stage must be respected[15].

For further guidance, please see Royal College of Surgeons (RCS) (2016) Professional standards for cosmetic surgery and GMC (2016) Guidance for doctors who offer cosmetic interventions.

3.22 Consent to visual and audio recordings

GMC guidance[16] states that consent to make the recordings listed below will be implicit in the consent given to the investigation or treatment, the results of which form part of the service-user's care record and will be available to other clinicians who the service-user consults in the future.

- Images of internal organs or structures
- Images of pathology slides
- Laparoscopic and endoscopic images
- Recording of organ functions

- Ultrasound images
- X-rays

Consent must be obtained before making recordings for teaching, training, the assessment of care practitioners and students, research or other healthcare related purposes (secondary purposes). It is good practice to get the patient's signed consent but if not practical, oral consent must be obtained. Signed consent or a record of oral consent must be stored with the recording.

Before making any recording, explain the purpose of the recording and how it will be used, how long the recording will be kept and how it will be stored. People must be made aware that they may withhold or withdraw consent at any time without the quality of their care being compromised.

For more detailed guidance please refer to GMC (2013) Making and using visual and audio recordings of patients. Additional advice can also be sought from the Information Governance Manager.

3.23 Consent to diagnostic investigations

Some procedures are primarily technical investigations carried out at the request of a referring care practitioner, for example, invasive radiological procedures and clinical investigations. In these cases, the referrer must explain to the patient how the proposed procedure fits into the plan of care and which reasonable alternatives exist. The referrer must also be able to explain in broad terms, the material risks associated with the procedure for which they are being referred.

On the day, the care practitioner responsible for performing the procedure must ensure that the patient has been given enough time and the appropriate information to make an informed decision and be in a position to answer any further questions the patient may have before undertaking it. The care practitioner will then be in a position to confirm that valid consent has been given.

3.24 Consent for the processing, analysis and storage of clinical samples

Samples of tissue, blood, body fluids or other biological materials are often obtained for analysis following a clinical consultation. The care practitioner takes a history from the service-user and may or may not perform a clinical examination before deciding which tests to perform. In the case of surgery, it may be decided to remove a piece of tissue for therapeutic and/or diagnostic reasons[27]. It is important to understand that additionally, the biological material that is submitted for laboratory investigation will be retained for a reasonable period and that it may be used anonymously for internal quality control, research, and development of new laboratory methods. The care giver must explain this to the service user, who may decline to consent to these activities and if they do decline the care practitioner must ensure the laboratory is made aware.

The responsibility to obtain valid consent lies with the care practitioner so it is appropriate for laboratory staff to presume that the care practitioner or the person to whom the task of obtaining and sending the sample was delegated to, has obtained valid consent. It is equally reasonable to assume that this consent extends to additional testing that may be indicated by the results of initial tests and it is important that this is explained to the patient by the care practitioner. The laboratory is not required to confirm this. It should also be understood by all parties (and it is the care practitioner's responsibility to ensure the service-user understands), that the results of investigations will become part of the service-user's care record and will be available to other clinicians who the service-user consults in future.

As a clinical scenario develops, consent for processing and analysing samples is valid if a further investigation remains within the scope of the original consent and if the service-user has been informed that further investigations may be required. Effective communication between laboratory staff and clinical staff is essential in such circumstances.

Remember, service-users have the right to exclude the performance of specific tests. If a potentially valid investigation is excluded from the consent, it is important that the care practitioner advises the laboratory of this.

3.25 Consent to participation in research

The principles set out within this document apply more widely to include decisions on taking part in research. GMC[17] advises that doctors who are involved in research *'must be satisfied that you have consent or other valid authority before you carry out any examination or investigation, provide treatment or involve patients or volunteers in teaching or research'.*

The general principles of consent are applicable to participation in research;

- Does the patient have capacity to consent to participation?
- Is consent to participate given voluntarily?
- Has the patient received sufficient information and has this been understood?
- How is this communicated?
- Who has responsibility for seeking consent?

The key elements of the discussion about the decision-making process must be recorded and where practical, signed consent should be requested.

With the participant's consent, the General Practitioner (GP) and other care practitioner's responsible for their care, should be informed about their involvement in the research project and any other information necessary to continuing care. This applies to participants who are both patients and healthy volunteers. If a participant objects to this, the potential consequences of not sharing such information should be discussed. If the participant continues to object, this decision must be respected, unless sharing is justified in the public interest.

For more detailed guidance please refer to GMC (2013) Good practice in research and consent to research

Advice must always be sought from the local research ethics committee.

3.26 Consent to student participation

Patients should be asked if they consent to being observed, examined and treated by students. It should be made clear to patients that they have the right to refuse without detriment to the care that they receive. Students should always introduce themselves to patients, including identity and status.

Where the procedure will further the care of patient, for example, taking a blood sample, then if the student is appropriately trained in the procedure, the fact that it is carried out by a student does not alter the nature and purpose of the procedure. It is therefore not a legal requirement to tell the patient that the person carrying out the procedure is a student, although it would always be best practice to do so. The general principles of consent must be followed.

Where the proposed procedure is to further the education of the student, it is essential to explain this to the patient. Consent to this must also be documented in the patients' medical notes.

3.27 Consent in an emergency situation

When an emergency arises and it is not possible to find out a patient's wishes, patients can be treated without their consent. However, the treatment must be immediately necessary to save their life or to prevent a serious deterioration of their condition.

Ongoing care should be provided on this basis for as long as the patient lacks capacity. If the patient regains capacity whilst in care, they must be informed about what has been done and why; this conversation should take place as soon as they are sufficiently recovered to understand[11].

The College of Emergency Medicine (CEM) [18] provides comprehensive information on this issue. However, please note that the reference to the *Bolam* test is out-dated and the principles in *Montgomery* must be applied.

3.28 Consent and the Mental Health (Jersey) Law 2016

The Mental Health (Jersey) Law 2016 provides ways of assessing, treating and caring for people who have a serious impairment or a disturbance in the functioning of their mind or brain to the extent that this puts them or other people at risk.

The MHL sets out when:

- People with an impairment or a disturbance in the functioning of their mind or brain can be detained in hospital for a period of assessment or treatment.

- People who are detained can be given treatment for the impairment or disturbance without their consent and,

- People with an impairment or a disturbance in the functioning of their mind or brain can be made subject to Guardianship in order to protect them or other people.

The MHL does not distinguish between people who have capacity to make decisions and those who do not. Many people subject to the provisions of the MHL have the capacity to make decisions for themselves. Most people who lack capacity to make decisions about their treatment will never be affected by the MHL, even if they need treatment for an impairment or a disturbance in the functioning of their mind or brain (CSDL (2016) Code of Practice, p.144).

For more detailed information please see MHL Code of Practice. This also lists the types of treatment for which consent and a second opinion would be required.

3.29 Consent for prescribing and administering unlicensed medication

The term 'unlicensed medicine' is used to describe medicines that are used outside the terms of their license or which have no license. However, there are clinical situations when the use of unlicensed medicines or use of medicines outside the terms of the license may be judged by prescriber to be in the best interest of the patient on the basis of available evidence[24].

The general principles of obtaining valid consent apply; capacity, voluntariness and appropriate information.

Where current research supports the use of a medicine outside the terms of its licence, it may not be necessary to draw attention to the licence when seeking consent. However, it is best practice to give as much information as patients require. If there is little evidence to support the use of an unlicensed medication, you must explain this to the patient[25].

For more detailed guidance please refer to GMC: Good practice in prescribing and managing medicines and devices and HCS medicines policy.

3.30 Consent to off-island treatment

Ultimately, the responsibility for ensuring that valid consent has been obtained rests with the practitioner providing the treatment. However, the referring practitioner has a duty to explain why the care cannot be provided on-island and ensure that they are referring to a service / practitioner who provides the care to a standard that is

recognised by HCS. This information must also be provided to the patient to facilitate the decision making process.

The referral and treatment process requires the relevant part of the service-users medical records to be shared with the overseas facility in order to facilitate treatment and ensure patient safety and quality of care. Under the Data Protection (Jersey) Law 2018, consent to share the relevant part of the records is not specifically required.

3.31 Consent and the Law Officers' Department

The Safeguarding Team at the Law Officers' Department (LOD) can be contacted during office hours for advice in relation to consent matters. However, such situations should be anticipated so that advice can be sought well in advance i.e. before an emergency situation develops out-of-hours.

Applications for advice to the LOD must be made by the Consultant in charge of the service-users care or the Medical Director.

4. PERSONS UNABLE TO MAKE DECISIONS

A person lacks capacity in relation to a matter if at the material time they are unable to make a decision for themselves in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain[5]. The CSDL[7] provides a framework to support people (over the age of 16 years) to make decisions for themselves or, failing that, to ensure that decisions are made for the person in the persons best interests.

It is underpinned by five core principles. Of relevance to those people who lack capacity are:

Principle 4: Anything done for or on behalf of a person who lacks capacity must be done in their best interests.

Principle 5: The purpose for which an act is done or a decision is made on behalf of a person who lacks capacity should be achieved in ways that are least restrictive to the person concerned.

The care practitioner providing treatment or care must decide what is in a person's best interests by taking the following actions[7]:

1. <u>Encourage participation</u>

All practical and appropriate steps must be taken to encourage and support the person lacking capacity to participate as fully as possible in any act done for or any decision affecting that person including their presence at any discussions in relation to their care and treatment. In addition, consider using simple language or illustrations and choosing a time / location where the patient feels most at ease.

2. Identify all relevant circumstances

Try to identify all the points that the person who lacks capacity would take into account if they were making the decisions or acting for themselves.

3. Find out the person's views

So far as possible, any determination must include consideration of the past and present wishes and feelings of the person lacking capacity as to the matter in question (in particular if they have been written down), any religious, cultural or moral beliefs or values of that person which would be likely to influence that persons decision if that person did not lack capacity and any other factors which that person would be likely to consider if they did have capacity.

In a recent report, the Law Commission (2017) states there is clear evidence that best interest decisions regularly fail to give any weight or prioritisation to the person's wishes and feelings[20].

4. Avoid discrimination

Determination as to what is in the best interests of a person lacking capacity must not be made on the basis of the person's age, appearance or any other aspect of his or her condition or behaviour.

5. Assess whether the person might regain capacity

Consideration must be given as to whether the person is likely to regain capacity and if so, whether the decision can wait until such time.

6. Consulting others

Where practical and appropriate, consult and consider the views of anyone engaged in caring for that person or interested in that person's welfare, any individual named by the person lacking capacity as someone to be consulted on the matter in question, any individual on whom authority is conferred, such as an ICA or any delegate appointed by the Court.

7. Life-sustaining treatment

Any decision relating to life-sustaining treatment must not be regarded as being in the best interests of a person lacking capacity if the decision is motivated by a desire to bring about that person's death.

In reference to *Principle 5,* any care practitioner making a decision on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedom or whether it is necessary to act at all.

For more detailed guidance on capacity, please refer directly to CSDL 2016 and CSDL 2016 Codes of Practice.

5. YOUNG PERSONS

5.1 Does the young person have capacity to consent?

The Consent to Medical Treatment (Jersey) Law 1973 provides that young people 16 years of age and over may give valid consent to surgical, medical or dental treatment and its associated procedures. However, there may be a question as to whether all young people aged 16-17 years have capacity to consent to treatment.

The requirements for valid consent are the same as for as adults. For consent to be valid, it must be:

- Given by a person with capacity to consent or refuse consent to the intervention in question, or any other legal decision maker,
- Given voluntarily and freely, without pressure or undue influence being exerted on the patient either to accept or refuse treatment and,
- Based on appropriate information and understood (informed).

Where a young person has the capacity to consent to treatment or care, their decision must be respected including refusal of treatment.

5.2 Has the young person received sufficient information?

The young person must receive the appropriate information.

5.3 Is consent given voluntarily?

Although a young person may have the capacity to consent, this is only valid if it is given voluntarily. This requirement must be considered carefully; young people may be subject to undue influence by their parent(s), other carers or a sexual partner. It is important to establish that the decision is in fact their own[8].

5.4 Young person with capacity refusing treatment

Where a young person has the capacity to consent to treatment or care, their decision must be respected; this includes refusal of treatment.

5.5 Young person unable to make a decision about care / treatment

If a young person does not have the capacity to make a decision, the decision should be made in the young person's best interests; either by the person with parental responsibility or by another appropriate decision maker, following the processes in the CSDL[7]. Even where a young person lacks capacity to consent for themselves, it is

good practice to involve the young person as much as possible in the decision-making process.

5.6 Parental responsibility

Those with parental responsibility include:

1. The child's mother, unless the child is legally adopted by someone else.

2. The child's father, if he was not married to the mother at the time of the birth if named on the birth certificate (applies only to births registered after the 2nd December 2016).

3. The child's father, if he was married to the mother at the time of the birth, or if the child is jointly adopted.

4. Unmarried fathers can acquire parental responsibility in several different ways;
   a. Marry the mother of the child and re-register the child's birth.
   b. A formal parental responsibility agreement between himself and the child's mother.
   c. Apply for a parental responsibility agreement by application to the Royal Court.

5. A person in whose favour the court has made a residence order concerning the child.

6. The Minister, if the child is subject to a Care Order (including an Interim Care Order) or an Emergency Protection Order (also referred to as Looked After Children (LAC)).

In the case of parents divorcing, the father retains parental responsibility, provided that he had parental responsibility when married. The parent with whom the child lives with does not have more powers than the other parent.

It is essential that those making decisions are clear about who has parental responsibility and that they always request copies of any court orders for reference on the child or young person's medical or social services record. These orders may include but not limited to residence orders, contact orders, interim and full care orders, and evidence of appointment of tuteur or a guardian (Article 7 Children's Law). If the parents of a child or young person are separated, and the child or young person is living with one parent, the person responsible for the care and treatment of the patient should try to establish whether there is a residence order and if so, in whose favour.

Once it is established who has parental responsibility for the child or young person, the person responsible for the care and treatment of the child or young person must determine whether the person with parental responsibility has the capacity to make a decision about the child or young person's treatment and whether the decision is within the scope of parental control. It should also be noted that the exercise of parental responsibility should be consistent with the child's developing capacity.

Under the Children Law, consent to treat a child or young person is needed from only one person with parental responsibility, however it is good practice to involve all those with parental responsibility and any others with responsibilities in caring for the child in the decision making process and, where possible, to resolve matters by agreement. However, if one person with parental responsibility strongly disagreed with the decision to treat and was likely to challenge it in court, it might be appropriate to seek a declaration from the court that the treatment is in the child's best interests and can be given.

Consent given by one person with parental responsibility is valid even if another person with parental responsibility withholds consent. Where persons with joint parental responsibility disagree as to whether specific interventions, for example, male circumcision, are in the child's best interests, it is advisable to refer these decisions to the Royal Court.

There is no local legislation related to the decisions that a person with parental responsibility has a right to make on a young person's or child's behalf where the child lacks capacity. These type of questions can arise where a decision relates to proposed treatment which is particularly invasive or controversial. Care practitioners should seek advice where they are unsure whether a person(s) with parental responsibility should make such a decision. Furthermore, where there is doubt about whether a parent is acting in the interests of the young person or child, do not rely on this consent and seek additional advice.

Parental responsibility lasts until a child reaches 18 years of age.

5.7 Person with parental responsibility refusing consent

Where necessary, the Royal Court can overrule a refusal by a person with parental responsibility. In situations where there is continuing conflict between those with parental responsibility and care practitioners and the young person is not able to provide valid consent, the Royal Court should be involved to clarify whether the proposed care / treatment or the withholding of treatment is in the young person's best interest.

Parental refusal must only be directly overridden in an emergency. In an emergency, it is justifiable to treat a young person who lacks capacity without the consent of a person with parental responsibility, provided it is not practicable to obtain consent in time and if the treatment is necessary to the survival or health of the young person.

5.8 Consent to participation in research

GMC[21] gives specific advice about research involving children and young people; the main points are summarised below.

Children and young people should not usually be involved in research if they object or appear to object in either words or actions, even if their parent(s) consent. If they are

able to consent for themselves, care practitioners should consider involving their parents, depending on the nature of the research.

Pressure must not be applied to children, young people or their parents to consent to research in the expectation of therapeutic, financial or any other benefit.

Before involving young persons or children in research, advice must be sought from the local research ethics committee.

6. CHILDREN

6.1 Young children and babies

When babies or young children are being cared for in hospital, it will not usually be practical to seek their parents' consent on each occasion for every routine intervention such as blood or urine test or x-ray. However, you should remember that, in law, such consent is required. Where a child is admitted, you should therefore discuss with their parent(s) what routine procedures will be necessary, and ensure that you have their consent for these interventions in advance. If parents specify that they wish to be asked before particular procedures are initiated, you must do so, unless the delay involved in contacting them would put the child's health at risk.

6.2 Children under 16yrs with capacity

The *Gillick*[22] competency and *Fraser*[6] guidelines help balance the rights and wishes of children with the responsibility of care practitioners to keep children safe from harm. However, they are not interchangeable; *Gillick* competence refers to the assessment that doctors could make in regards to whether a child under 16 years has the capacity to consent to treatment without parental or guardian consent. The *Fraser* guidelines refer specifically to the responsibility of doctors to ensure adequate capacity of children specifically on receiving contraceptive prescription and advice; it makes no comment on the capacity of children for any other treatments or procedure

Gillick competency refers to a legal case in England where the question of how to assess a child's capacity to consent to medical treatment was considered. The principles established in this case are applicable in Jersey;

"...*whether or not a child is capable of giving the necessary consent will depend on the child's maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent*."

[6] Fraser guidelines specifically relate to giving contraceptive advice and treatment, treatment of sexually transmitted infections and termination of pregnancy to those under 16 without parental consent. Advice can be given in this situation as long as:(s)he has sufficient maturity and intelligence to understand the nature and implications of the proposed treatment, (s)he cannot be persuaded to tell her parents or to allow the doctor to tell them, (s)he is very likely to begin or continue having sexual intercourse with or without contraceptive treatment, his / her physical or mental health is likely to suffer unless given advice or treatment and the advice or treatment is in the young person's best interests.

The concept of *Gillick* competence is said to reflect a child's increasing development to maturity. The understanding for different interventions will vary considerably. A child under the age of 16 years may have the capacity to consent to some treatments but not to others; thus a child's capacity to consent should be assessed carefully in relation to each decision that needs to be made.

If a child is *Gillick* competent and is able to give voluntary consent after receiving the appropriate information, that consent will be valid; additional consent by a person with parental responsibility is not required. However, where possible it is good practice to involve the child's family in the decision-making process, provided the child consents to their information being shared.

Where advice or treatment relates to contraception or the child's sexual or reproductive health, the care practitioner should explore with the child the benefits of informing the parents or allowing the care practitioner to do so. If after this discussion, the child does not want to inform their parents, advice and / or treatment should still be given if the care practitioner considers that the child is very likely to begin or continue to have sexual intercourse with or without advice or treatment, and that unless they receive the advice or treatment, then the child's physical or mental health is likely to suffer.

6.3 Is consent given voluntarily?

Although a young person may have the capacity to consent, this is only valid if it is given voluntarily. This requirement must be considered carefully; young people may be subject to undue influence by their parent(s), other carers or a sexual partner. It is important to establish that the decision is in fact their own.

6.4 Has the child received sufficient information?

Once the first two requirements have been satisfied, the last requirement for the consent to be valid is that the young person must receive the appropriate information.

6.5 Child with capacity refusing treatment

Where a child has capacity to make the decision in question, a person with parental responsibility cannot override this decision. However, if the consequences of refusing such consent are grave, a representation can be made to the Royal Court to examine the child's capacity to make the decision and whether it would be appropriate to order treatment despite a refusal.

See section 7.3

6.6 Child without capacity

If a child does not have the capacity to make a decision, consent can be given on their behalf by any one person with parental responsibility or by the Royal Court. Those giving consent on behalf of a child must themselves have the capacity to consent to the intervention in question, be acting voluntarily and be appropriately informed. The power to consent must be exercised according to the 'welfare principle': the child's welfare must be paramount.

6.7 Parental responsibility

See section 5.6.

6.8 Person with parental responsibility refusing consent

See section 5.7.

6.9 Participation in Research

See section 5.8.

7. WITHDRAWING AND WITHHOLDING LIFE SUSTAINING TREATMENT

7.1 General principles

The legal and ethical principles underpinning valid consent are the same for all medical interventions, including decisions to withdraw or withhold life-sustaining treatment. However, the issues surrounding seriously ill or dying patients are necessarily more grave and sensitive.

A care practitioner's legal duty is to care for a patient and to take reasonable steps to prolong life. Although there is a strong presumption in favour of providing life-sustaining treatment, there is no absolute obligation to prolong life irrespective of the consequences for the patient[8].

There is no legal distinction between withdrawing and withholding life-sustaining treatment.

A person with capacity may decide either contemporaneously or by a valid ADRT that they have reached a stage where they no longer wish treatment to continue. If a person lacks capacity and no legal decision-maker has been appointed, this decision must be taken in their best interests and in a way that reflects their wishes.

In an emergency situation, where there is doubt as to the appropriateness of treatment, there should be a presumption in favour of providing life-sustaining treatment. When more time is available and the patient lacks capacity, all those concerned with the care of patient can potentially make a contribution to the assessment.

The discussions and basis for all decisions must be recorded in the patient's notes.

There is an important distinction between withdrawing or withholding treatment that is of no benefit to the patient or is not in the patients' best interests and taking a deliberate action to end the patients' life. A deliberate action intended to cause death is unlawful.

There are circumstances when continuing or providing life-sustaining treatment stops providing a benefit to a patient and is not clinically indicated. Care practitioners should discuss the situation with a patient with capacity and agree if and when the patient no longer wishes treatment to continue. If the person lacks capacity, this decision must be taken in their best interests and in a way that reflects their wishes, beliefs and values.

7.2 Persons with capacity

If a person with capacity to make the decision in question refuses life-sustaining treatment or requests withdrawal of life–sustaining treatment, comply with this decision, even if it results in the person's death. If a refusal is ignored, care practitioners will be treating the person unlawfully[7].

The case of *R (Burke) v GMC* [2005] 3 FCR 169[23], established that an adult patient with capacity does not have the right to demand treatment that is not clinically indicated. Where a patient with capacity indicates his / her wish to be kept alive by the provision of artificial nutrition and hydration (ANH), a duty of care requires the provision of ANH whilst it continues to prolong life.

A person cannot demand that a care practitioner does something unlawful, such as assisting suicide.

7.3 Young person and child with capacity

If a young person or child with capacity makes such a request or refusal, it is possible that such a refusal could be overruled if potentially it would lead to the death or to severe, permanent injury. To take a decision which may result in death requires a very high level of understanding; many young people / children with capacity / *Gillick* competence would be considered to lack the capacity to make such a grave decision.

It is not a legal requirement to continue a child's life-sustaining treatment in all circumstances. Where a child is suffering an illness where the likelihood of survival even with treatment is extremely poor and treatment will pose a burden to the child, it may not be in the best interests of the child to continue treatment.

7.4 Persons unable to make a decision

[7] *Re B (Adult, refusal of medical treatment) [2002] 2 All ER 449.*

If a person lacks capacity and has not made a valid and applicable ADRT, the provisions of the CSDL[7] will apply and any decision must be based on the best interests of the person. All reasonable steps that are in the person's best interest should be taken to prolong their life, unless there is an appointed decision maker.

Where a patient has indicated whilst they had capacity, his or her wish to be kept alive by the provision of ANH, a duty of care requires the continued provision of ANH whilst such treatment continues to prolong life. Where life depends upon the continued provision of ANH, ANH will be clinically indicated.

7.5 Children lacking capacity

If a child lacks capacity, it remains good practice to involve the child as much as possible and as is appropriate in the decision-making process. Any decision to withdraw or withhold life-sustaining treatment must be made in the best interests of the child. In the context of withholding treatment, the best interests of the child should be interpreted more broadly than medical interests and should include emotional and other factors[8].

A person with parental responsibility for a child or young person is legally entitled to give or refuse consent to treatment. However, there is a strong presumption in favour of preserving life but where treatment would be futile, there is no obligation to provide such treatment. A person with parental responsibility cannot demand a particular treatment to be continued where the burden of treatment outweighs the benefits for the child. If there is disagreement between those with parental responsibility and the clinical team concerning the most appropriate course of action, the matter should be referred to the Royal Court. The views of the parents are very influential but in exceptional cases, English Courts have been willing to authorise the withdrawal of life-sustaining treatment against parents' wishes where they conflict with the best interests of the child.

8. DEVELOPMENT AND CONSULTATION PROCESS

8.1 Consultation Schedule

This Government of Jersey Law Officer's Department was sent this document for review in 2018.

Name and Title of Individual	Date Consulted
Managing Director (JGH)	May/June 2018
Managing Director (CSS)	May/June 2018
Director of Operations (JGH & CSS)	May/June 2018
Divisional Lead (Surgical Services)	May/June 2018
Divisional Lead (Medical Specialities & Emergency Care)	May/June 2018
Divisional Lead (Clinical Support Services)	May/June 2018
Divisional Lead (Operational Support Services)	May/June 2018
Divisional Lead (Theatre & Anaesthesia)	May/June 2018

Chief Nurse	May/June 2018
Director of Governance, Quality & Nursing (CSS)	May/June 2018
Head of Nursing & Governance (JGH)	May/June 2018
Medical Director (JGH & CSS)	May/June 2018
Consultant Group	May/June 2018
Head of Midwifery	May/June 2018
Chief Ambulance Officer	May/June 2018
Acting Head of Occupational Therapy	May/June 2018
Head of Physiotherapy	May/June 2018
Chief Clinical Physiologist	May/June 2018
Chief Pharmacist	May/June 2018
Pathology Manager	May/June 2018
Information Governance Manager	May/June 2018
Legal Administration Manager	May/June 2018
Designated Nurse Safeguarding	May/June2018
Capacity Legislation Team	May/June 2018

Name of Committee / Group	**Date of Committee / Group meeting**
Medical Staffing Committee	July 2018

9. REFERENCE DOCUMENTS

[1] *Montgomery* v *Lanarkshire Health Board* [2015] UKSC 11.

[2] *Webster* (A Child) v. *Burton Hospitals NHS Foundation Trust* [2017] EWCA Civ 62.

[3] *Bolam* v. *Friern Hospital Management Committee* [1957] 1 WLR 583.

[4] Department of Constitutional Affairs (2007) Mental Capacity Act 2005 Code of Practice, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf, London, TSO, Last accessed 2 May 2018.

[5.] The Legal Dictionary http://legal-dictionary.thefreedictionary.com/negligence, Last accessed 30 April 2018

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10. LEGISLATION

- Capacity and Self-Determination (Jersey) Law 2016
- Children's Act 1989
- Children (Jersey) Law 2002
- Consent to Medical Treatment (Jersey) Law 1973
- European Convention on Human Rights
- Family Reform Act (1987)
- Human Rights Act (1998)
- Human Rights (Jersey) Law 2000
- Mental Health Act (1983)
- Mental Capacity Act (2005)

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12. GLOSSARY OF TERMS / KEYWORDS AND PHRASES

- Advance decision to refuse treatment (ADRT)

A decision made by a person with capacity to make decisions about future care and treatment for times when they lack the capacity to make the decisions for themselves.

- Battery

Battery is the intentional and direct application of force to another without consent.

- Best interests

Any decision made, or anything done for a person who lacks capacity to make specific decisions, must be in the person's best interests; taking into account the person's wishes and feelings and their physical, psychological, emotional and social needs[4].

- Capacity

Capacity is the ability to make a decision.

- Consent

Consent refers to the rights of patients to decide what, if any, clinical care they are to receive and the duty of the care practitioner to ensure that patients have given their permission prior to any care-giving, treatment, examination or intervention.

For consent to be valid, it must be:

- Given by a person with capacity to consent or refuse consent to the intervention in question, or any other legal decision maker,
- Given voluntarily and freely, without pressure or undue influence being exerted on the patient either to accept or refuse treatment and,
- Based on appropriate information and understood (informed).

- Child(ren)

For the purpose of this policy, refers to people aged under 16 years.

- Decision-maker

A decision-maker may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for themselves: it is the decision-maker's responsibility to work out what would be in the best interests of the person who lacks capacity. A range of different decision-makers may be involved with a person who lacks capacity to make different decisions.

- Care professional / practitioner / provider

A person who provides any form of health or social care. This ranges from those individuals providing assistance with personal care to those performing surgical procedures. At times the terms are used interchangeably.

- Independent Capacity Advocate (ICA)

An ICA may be involved in the decision making process relating to serious medical treatment or changes in long-term residence where a person has nobody else who is

willing and able to represent them or be consulted in the process of working out their best interests.

- Lack of capacity

A person lacks capacity in relation to a matter if at the material time he / she is unable to make a decision for him / herself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain[7].

- Negligence

Conduct that falls below the standards of behaviour established by law for the protection of others against unreasonable risk of harm. A person has acted negligently if he or she has departed from the conduct expected of a reasonably prudent person acting under similar circumstances[5].

- Parental responsibility

Refers to the rights, duties, powers, responsibilities and authority which by law, a parent has in relation to a child.

- Person / patient

An adult who receives any form of care. Reference to persons also includes clients and service-users. At times the terms are used interchangeably.

- Young person

For the purpose of this policy, refers to people age 16-17 years.

13. IMPLEMENTATION PLAN

A summary of how this document will be implemented.

Action	Responsible Officer	Timeframe
Circulate via communication to all managers and consultants.	Patient Safety Officer	As soon as ratified
Managers to ensure their staff are aware of the new policy through, for example, team briefing and staff meetings. Managers must ensure staff have read the policy..	All Managers	End March 2019

Principles of consent underlying this policy presented in conjunction with the Capacity training session on the essential study days for Nursing staff.	Patient Safety Officer	During 2018

14. APPENDICES

Appendix 1 Case law

The *Bolam* test

- *Bolam* v. *Friern Hospital Management Committee* [1957] 1 WLR 583.

The plaintiff suffered harm in hospital whilst undergoing ECT treatment. It was held that the relevant standard of care was that of 'the ordinary skilled man exercising and professing to have that special skill'.

According to *Bolam,* 'a doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art'. In *Sidaway* v *Board of Governors of Bethlehem Royal Hospital,* the *Bolam* standard was applied to the information given as well as the treatment chosen and the method of carrying out.

Gillick competency

- *Gillick* v *West Norfolk & Wisbech Area Health Authority* [1985] UKHL 7.

In 1982, Mrs Gillick took her local health authority and the Department of Health and Social Security to court in an attempt to stop doctors from giving contraceptive advice or treatment to children under the age of 16 years without parental consent.

The case went to the House of Lords where Mrs Gillick's claims were dismissed:
"whether or not a child is capable of giving the necessary consent will depend on the child's maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent."

Standard of informed consent

- *Montgomery* v *Lanarkshire Health Board* [2015] UKSC 11.

Nadine Montgomery was a woman with diabetes, who raised concerns with her the consultant obstetrician (Dr McLellan) that she might not be able to deliver vaginally. Dr McLellan did not discuss the risk of shoulder dystocia; withholding the information on the grounds that it might have discouraged her from having a vaginal delivery. Her child was born with serious disabilities as a result of shoulder dystocia during delivery.

The law now requires a doctor to take '*reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment and of any reasonable alternative or variant treatment'.* Material risk is defined in law as either a risk to which a reasonable person in the patients position would be likely to attach

significance, or a risk that a doctor knows – or should reasonably know – would be deemed of significance by this particular patient.

The effect of coercion/pressure on patient consent

- *Re T (Adult) [1992] 4 All ER 649.*

T, a 20-year-old pregnant woman, was injured in a car accident and developed complications that required blood transfusions. She did not indicate on admission that she was opposed to receiving transfusions but after spending some time with her mother, who was a practising Jehovah's Witness, she decided to refuse the treatment.

The Court of Appeal considered that T had been pressurised by her mother and that her ability to decide about the transfusions was further impaired by the drugs with which she was being treated. The Court allowed the blood transfusions to proceed. A patient's consent to a particular treatment may not be valid if it is given under pressure or duress exerted by another person.

Capacity to refuse treatment

- *Re MB (Adult, medical treatment)* [1997] 38 BMLR 175 CA.

MB needed a caesarean section, but withheld consent to this procedure on account of her needle phobia. The hospital obtained a judicial declaration that it would be lawful to carry out the procedure, a decision that MB appealed. However, she subsequently agreed to induction of anaesthesia and her baby was born by caesarean section.

The Court of Appeal upheld the judges' view that MB had not, at the time, been competent to refuse treatment, taking the view that her fear and panic had impaired her capacity to take in the information she was given about her condition and the proposed treatment.

- An individual's capacity to make particular decisions may fluctuate or be temporarily affected by factors such as pain, fear, confusion or the effects of medication.
- Assessment of capacity must be time and decision-specific.

Right of a patient who has capacity to refuse life-prolonging treatment

- *Re B (Adult, refusal of medical treatment) [2002] 2 All ER 449*

Following an illness, patient B became tetraplegic and reliant on a ventilator. She requested that the ventilator that was keeping her alive be switched off and claimed that the continued provision of artificial ventilation against her wishes was unlawful. An application was made to the Court to decide whether patient B had the capacity to

make the decision about whether the ventilator should be removed. The Court held that she had capacity to refuse treatment and had therefore been treated unlawfully.

Where a patient has the capacity to make decisions about treatment, they have the right to refuse treatment, even where the consequences of such decision could lead to their death. If a care practitioner feels unable to carry out the wishes of the patient, their duty is to find another doctor who will do so.

No legal right to demand a treatment that is not clinically indicated

- *R (Burke)* v. *GMC* [2005] 3 FCR 169.

Mr. Burke suffered from a congenital degenerative brain condition, meaning he would eventually need artificial nutrition and hydration (ANH). Medical evidence indicates that he is likely to retain full cognitive faculties even during the end stage of this disease and that he will retain, almost until the end, insight and awareness of the pain, discomfort and extreme distress that would result from malnutrition and dehydration. He was concerned that before those final stages, the GMC guidelines may lead doctors withdrawing ANH when he wished to continue to receive it no matter the pain and suffering. He sought a declaration that the guidance was incompatible with the ECHR.

This case established that an adult patient with capacity does not have the legal right to demand treatment that is not clinically indicated. However, where a patient with capacity indicated his / her wish to be kept alive by the provision of ANH, the care practitioner's duty of care will require them to provide ANH while such treatment continues to prolong life.

Application of the *Montgomery* principle

- *Kathleen Jones* v. *Royal Devon and Exeter NHS Foundation Trust* [2015] (unreported).

Mrs. Jones suffered from a central spinal canal stenosis and after trying a number of alternative treatments, elected to undergo surgery performed by Mr. Chan (a highly regarded Consultant Orthopaedic Spinal Surgeon). After having to cut short her holiday due to pain, Mrs. Jones saw her GP for advice on whether it was possible to bring the surgery forward; she was advised that this would result in the surgery being carried out by a more junior surgeon. Mrs. Jones followed her GP's advice to wait for Mr. Chan to perform the operation.

Mrs. Jones was informed by a nurse just prior to going into theatre that Mr. Chan was not available and a different surgeon would be performing the surgery. Mrs. Jones was not afforded the opportunity to weigh up her options; she felt that she was "beyond the point of no return" and accordingly saw through the surgery. Unfortunately the operation did not go without complication and Mrs. Jones has been left with Cauda Equina syndrome.

Although the judge did not accept that the surgeon had been negligent in his conduct of the operation, he accepted expert evidence to the effect that there is a much lesser risk of such complications occurring where the surgery is carried out by a more experienced surgeon therefore it was *"more likely than not that Mrs. Jones would not have suffered the injury had her operation been performed by Mr. Chan".*

The Court found that Mrs. Jones had been deprived of the right to choose by whom she was operated on. However, in this case there is compelling evidence that the choice of surgeon was important to her. The fact that the consent form states that there is 'no guarantee as to the identity of the surgeon', this did not prevent the court from finding the Trust liable for not providing the surgeon chosen by the claimant.

Although only a county court decision, this demonstrates the wide-reaching applications of *Montgomery.* The patient's right to be fully informed is clear and the courts are prepared to back up where care practitioners fail to fulfil their duty to inform of all issues that are material to that particular patient.

- *Spencer* v. *Hillingdon Hospital NHS Trust* [2015] EWHC 1058

The claimant developed bilateral pulmonary emboli following surgery to repair an inguinal hernia.

The Court considered *Montgomery* and found that the defendant trust had failed to advise the Claimant of the risk of pulmonary embolus.

- *Webster* (A Child) v. *Burton Hospitals NHS Foundation Trust* [2017] EWCA Civ 62

Sebastian Butler was born on 7th January 2003. He was born with cerebral palsy and has profound physical and cognitive impairment. The High Court heard how Sebastian's mother, Ms Butler, had wanted to have her baby induced, but the Consultant advising Ms Butler did not wish her to be induced and wanted her labour to proceed to a natural delivery. As a result, Sebastian was left with life-changing disabilities and profound brain damage after his umbilical cord was compressed, meaning that his brain was starved of oxygen in the days prior to his delivery. It was agreed between the parties that his disabilities were caused by a brain injury as a result of a short period of cord compression, occurring 48-72 hours before his birth. It was further agreed that had he been delivered before 4 January 2002, he would have avoided the brain injury and its consequences.

The appellant lost her case at first instance; applying the Bolam test, the High Court found that there was a reasonable and responsible body of obstetric opinion that would have acted in the same way as the Consultant had done, and would not have altered the case management plan.

The appellant appealed to the Court of Appeal that held since *Montgomery*, it was not appropriate to apply *Bolam* and that they therefore had to consider what advice information her obstetrician should have given Ms Butler and what her response would have been. The Court of Appeal heard that had repeated ultrasound scanning been carried out, the distress that the foetus was showing and the fact that it was small for

its gestational age would have been identified. In that instance the mother would have wished to be induced as she wouldn't have wanted to delay the birth any longer.

Therefore, the Court of Appeal re-affirmed the decision in Montgomery, deciding that the mother's wish to be induced should have been followed. This decision underlines that the role of the doctor is as a medical advisor, and not as the decision maker.

In addition, it is clear that the courts will take a wide range of factors into consideration (including educational background), and that doctors are now required to have a deeper understanding of a patient's concerns.

- *Lisa Thefaut v Francis Johnston [2017] EWHC 497*

A surgeon was liable for his patient for having failed to give her full advice about the risks relating to surgery aimed at eradicating pain in her back and left leg.

The claimant stated that she consented to surgery in circumstances where the surgeon failed to give her full and accurate advice about the risks and benefits of a discectomy. She claimed that as a direct consequence of the comforting and optimistic advice that was given to her, she was reassured and this led to her giving consent. Mrs. Thefaut suffered further nerve damage as a consequence of the surgery. Mrs. Thefaut claims that she had been properly advised, she would have known that the chances of a full recovery were not as optimistic as portrayed and she would not have given her consent. In such circumstances she was advised that she would recover over time and her pain would resolve.

In relation to the issue of consent, the Court found that the surgeon fell below the standard required in law (*Montgomery).* On the evidence, the advice given to Mrs. Thefaut led to her giving consent in circumstances where she would not have consented if she had been given proper advice.

<u>The power of the Court to override parental consent</u>

- *Great Ormond Street Hospital v. Yates* [2017] EWHC 1909 (Fam) (24 July 2017).

Under the law, parents with parental responsibility have the power to give consent for their child to undergo, medical treatment if their child lacks the capacity to consent. However, a court has the power to override parental consent in the exercise of its independent and objective judgment in the child's best interest.

Charlie Gard was born with a rare medical condition called mitochondrial DNA depletion syndrome, causing severe physical and cognitive debilitation. Consequently, Charlie suffered from congenital deafness, severe epilepsy and could not move his arms or legs or breathe without the assistance of a ventilator. His prognosis was poor.

Charlie's parents then became aware of an experimental treatment. Despite the limited prospect of success, Charlie's parents were in contact with a medical professional who stated that the treatment was of possible benefit to and it was reasonable to attempt.

Before a decision could be made about whether to proceed with the treatment, Charlie suffered a series of severe seizures and his cognitive condition seriously deteriorated. His doctors at the hospital agreed that as a result of the brain damage that Charlie had suffered, the experimental treatment was almost entirely futile; possibility of prolonged suffering outweighed the tiny chance of benefit from the treatment.

Charlie's parents did not believe that Charlie's condition was as extreme as doctors maintained. Due to the conflict between Charlie's parents and the hospital, the hospital referred the matter to the UK High Court.

A series of litigation ensued in the UK courts and the ECHR; at every stage, the courts agreed with the hospital that the withdrawal of treatment was in Charlie's best interests.

Appendix 2 Overview of the consent process (adapted from the RCS (2016, p.20).

This process aims to optimise the time available for providing the required information and discussing options for treatment to facilitate patient decision. This process is aimed at persons with capacity.

Step	Task	Comments
1	Explain the diagnosis to the patient.	Ensure that the information is given in a format that the patient can understand. Explain the prognosis if untreated.
2	Explain the options for treatment.	Explain the risks and benefits of various treatment options side by side and ensure that not having any treatment is included amongst the options. Describe the likelihood of success of the various options and the impact that treatments will have on the patient's life.
3	Explain the consent and decision-making process so the patient understands what is expected of them.	Ensure that the patient understands that they are expected to make a supported decision, and their rights within this process. Do not assume that the patient will be familiar with the concept of supported decision-making and check whether they have a supporter.
4	Time for deliberation and private consideration of options for the patient	Where relevant, surgeons should allow sufficient time for patients to deliberate on available options and to consider their goals and wishes in terms of their treatment. This may include reading further information or accessing online resources to provide them with more information on their condition and treatment options.
5	Discuss the patient's wishes, needs, views and expectations regarding any treatment they might undertake.	It is important not to make assumptions regarding what a 'good' outcome from treatment would look like for the patient. Different patients will have different life priorities and different views regarding what the bet available outcome might be or what risks are acceptable to them. Sufficient time is given to ensure that the patient's views are understood and respected.

6	Discuss trade-offs with the patient in light of their needs, goals and expectations.	Explain how different options will or will not achieve their goals and any potential impact that the options will have.
7	Provide any relevant information not already covered, or any emerging information that may have altered the conditions surrounding the various options for treatment.	Is there any further information that would have a bearing on the decision that the patient is being asked to make that has not already been discussed and / or understood by the patient? If so, ensure that these factors are explained and if necessary go back to an earlier stage in the process and repeat in light of the new knowledge. This is of particular importance in cases where the process has spanned a period of time where changes may have occurred in the patient's condition or around the risks and benefits of any of the treatment options available.
8	Has the patient understood?	Prior to any decision it is imperative that the person seeking consent is satisfied that the patient has understood the information that they have been given and that any decision they make will be made independently and from an informed position.
9	Respect the patient's decision.	You must always respect the decision made by an adult patient with capacity.
10	The signing of the form and maintaining a decision-making record	The consent form as part of the decision-making record should be signed at the end of the discussion, provided the patient has made a decision. The patient should be given a copy of the form to review and retain. Details about the discussion with the patient and copies of any information given to the patient should be included in the patient's notes.