Principles of Consent
Guidance for nursing staff
Acknowledgements

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About this document

It should be noted that this guidance is specific to consent for physical interventions on living individuals. The following areas are therefore not included:

- participation in observational studies
- the use of personal information
- the use of organs or tissue after death.

It should also be noted that case law evolves over time and further legal developments may occur after this guidance has been issued. Registered nurses must remember their duty to keep themselves informed of legal developments which may have a bearing on their practice.

Although reference is made to a “registered nurse” throughout this document, the guidance and principles apply equally to student nurses and health care assistants.
Consent

Consent is defined as “permission for something to happen or agreement to do something” (Oxford English Dictionary). In relation to health care, it is a general legal and ethical principle that valid consent must be obtained before commencing an examination, starting treatment or physical investigation, or providing care. This principle reflects the rights of a person to determine what happens to their own bodies or what shapes the care and support they receive. It is fundamental to good practice. The Nursing and Midwifery Council (NMC) professional practice document for nurses and midwives, The Code (NMC, 2015a) states that registered nurses must:

(4.1) “balance the need to act in the best interests of all people at all times with the requirement to respect a person’s right to accept or refuse treatment”, and

(4.2) “make sure that you get properly informed consent and document it before carrying out any action”.

Registered nurses who do not respect this principle may be liable to both legal action by the person in their care and action by the NMC.

The requirement to gain consent has two purposes, one legal and the other clinical (Richardson V, 2013). The legal purpose is to provide those delivering treatment with a defence to a criminal charge of assault or battery or a civil claim for damages for trespass to the person. The clinical purpose comes from the fact that in most cases the co-operation of the person and the person’s confidence in the treatment or physical investigation, or the provision of care.

What is meant by “valid consent”? For consent to be valid, it must be given voluntarily and freely, without pressure or undue influence, by an appropriately informed person who has the capacity to consent to the intervention in question. Some people may feel pressurised, by relatives or carers for example, to accept a particular investigation or treatment. Registered nurses should be aware of this, and of other situations in which people might be vulnerable, for example, those resident in a care home, or in prison. In these situations it is essential to ensure that the person has considered the available options and has voluntarily reached their own fully informed decision.

What is meant by “informed consent”? Several recent and less recent judicial reviews and rulings by the Supreme Court have confirmed that the need for “informed consent” is a legal requirement (Montgomery v Lanarkshire Health Board [2015]). Many interventions are not a simple “yes/no” situation; it is not enough to provide adequate information to ensure consent for the examination, treatment and/or care. Sufficient evidence based information must be provided to the person to enable them to make a balanced and informed decision about their care and treatment. As well as a general explanation of the procedure there is also a duty to explain the risks inherent in the procedure and the risks inherent in refusing the procedure. Information must also be provided regarding alternatives to the proposed intervention. This will assist the person to make the decision to consent to, or refuse consent for a particular intervention, whilst respecting their right to autonomously decide what happens to them. Failing to meet this legal duty can give rise to an action in negligence if the person is subsequently harmed.

What is meant by “capacity to consent”? The ability to make decisions independently is often referred to as “having capacity”.

Principles underpinning UK mental health legislation and mental capacity legislation support “assumption of capacity”; that is, adults are presumed to have the ability to independently make decisions about and decide whether to agree to or refuse any aspect of their care, treatment and/or support.

A person who has capacity is able to provide or withhold consent for examination, treatment and/or care. If an adult makes a voluntary and appropriately informed decision to refuse care, treatment and/or support, then registered nurses must respect this decision.
UK legislation which provide safeguards in relation to capacity to make decisions independently explicitly require all practicable help and support to be provided to a person to enable the individual to make decisions about matters affecting them.

An elderly gentleman who lives in a care home has arthritis in his hands which makes it difficult for him to wash. Following a stroke he also has some mobility problems which contribute to urinary incontinence because he does not always make it to the toilet in time. His assessed needs indicate that he needs assistance with personal hygiene tasks, including showering/bathing. There is a risk that he may develop sacral skin breakdown because he is often sitting in underwear and trousers that are wet with urine. A nurse discusses the gentleman's care needs with him, explaining the potential for skin breakdown. The nurse also explains that there is an unpleasant odour and suggests that other staff and residents may start to notice this. The nurse proposes that he has a bath or shower every day and that one of the care staff could assist him. The gentleman declines stating that he does not like showers and that getting in and out of the bath would be too awkward for him. He says that he has always attended to his own personal hygiene and would like to continue to do so, despite the risk of his skin breaking down. The nurse is confident that the gentleman has understood all of the information provided and that he has weighed the information appropriately to make his own decision about assistance with personal hygiene tasks. The nurse understands that she cannot force the gentleman to accept assistance with personal care and respects the gentleman's decision to refuse help with his personal hygiene.

There are several ways in which a person can be helped and supported to make a decision for him or herself. This will vary depending on the decision to be made, the urgency of the decision and the individual circumstances of the person making the decision.

A person cannot be regarded as having been given all practicable help and support to make a decision unless steps have been taken by the person proposing the intervention, as far as is practicable.

The steps are:

- providing information in a way that is suitable to the person;
- ensuring that the time and place are appropriate; and,
- making sure that any persons whose involvement would help the person make the decision in question are present.

The steps are interconnected and are all equally important.

A person can only be regarded as “lacking capacity” and unable to independently make a decision about their care, treatment or support once all practicable help and support has been provided. “Unable to make a decision” means that the person:

a) is not able to understand the information relevant to the decision;

b) is not able to retain that information for the time required to make the decision;

c) is not able to appreciate the relevance of that information and to use and weigh the information as part of the process of making the decision; or,

d) is not able to communicate his or her decision (whether by talking, using sign language or any other means).

Whether the person has a particular condition is irrelevant to the question of whether he or she has capacity to make decisions in any matter. Assumptions about a person's capacity to make decisions about care, treatment and support
must not be based on the person’s age, disability, appearance, medical condition, their beliefs, their apparent ability to communicate or any other characteristic.

The relevant legislation also provide for a person to make what health and social care professionals might consider to be an “unwise decision”. Making unwise decisions does not amount to a “lack of capacity” to make decisions.

Registered nurses must be aware that a person’s ability to make decisions may depend on the nature and severity of their condition, or the difficulty or complexity of the decision. Some people will always be able to make simple decisions, but may have difficulty if the decision is complex or involves a number of options. Others may be able to make decisions at certain times but not others, because fluctuations in their condition impair their ability to understand, retain or weigh up information, or communicate their wishes. In situations where capacity to make decisions independently fluctuates, decision making about a particular intervention should be delayed until the person is able to provide valid consent.

Capacity to consent must always be considered according to the specific time, situation and decision.

Who can provide consent?

Adults must provide consent on their own behalf. No one, including parents, relatives and health and social care professionals, can give or withhold consent on behalf of another adult unless special legal provision* for particular purposes has been made for this.

What if the person does not consent to examination, treatment, care or support?

If a person has capacity to make decisions independently then their decision is binding and the proposed examination, treatment, care or support cannot proceed, even if you think their decision is wrong.

Advance decisions

The law allows for an adult to make a decision to refuse a treatment in the future if that decision is made at a time when the person had the capacity to make such a decision. Registered nurses must be aware that failure to respect such an advance refusal can result in legal action.

Advance decisions cannot require registered nurses to provide particular treatments (which may be inappropriate or illegal, for example assisted suicide). However, registered nurses may still provide essential care such as keeping a person warm, offering oral nutrition and hydration, and pain relief. It does not include force-feeding or the use of artificial hydration and nutrition. The courts have recognised that a person with capacity to make decisions has the

* This could include powers of attorney or a court appointed individual, appointed in accordance with the relevant legislation. Registered nurses should refer to the appropriate country specific legislation for guidance in these matters.

Relevant mental health legislation and capacity legislation (Mental Capacity Act 2005; Adults with Incapacity (Scotland) Act 2000, Mental Health (Northern Ireland) Order 1986, Mental Capacity Act (Northern Ireland) 2016, Mental Health (Scotland) Act 2015) make provision for the possibility of detention/deprivation of liberty and/or treatment for a mental disorder and its complications without the consent of the adult, or a young person aged under 18 years.

If an adult has been assessed as lacking the capacity to make a specific decision then there are formal legislative processes that allow for a decision about care, treatment or support to be made on their behalf. These are commonly known as “best interests’ decisions”. Best interests are not confined to best medical interests. Most organisations will have established protocols based on legislative requirements and recognised good practice principles. Registered nurses must adhere to these protocols when assisting with making best interests decisions proposed for a person who lacks capacity.

Whether a formal assessment of capacity, or in some cases a legal opinion, is required depends on the seriousness and/or the potential consequences of the proposed intervention. These situations are guided by legislation and organisational policies and procedures.

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right to refuse food and fluids. Towards the end of such a period a person is likely to lose capacity to make decisions. The courts have ruled that if a person has, whilst competent, expressed the desire to refuse food until death supervenes, the person cannot be force fed or fed artificially when a lack of capacity has developed.

**Children and young people**

It is particularly important that registered nurses working with children and young people understand the laws around capacity, and child and parental consent, including giving and refusing consent for the implementation of any treatment or intervention.

Young people aged 16 -17 are entitled to provide consent for their own medical treatment in the same way as adults. Scottish legislation (Age of legal capacity (Scotland) Act 1991) provides a legal basis for a young person under the age of 16 years to consent on his or her own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending them, they are capable of understanding the nature and possible consequences of the procedure or treatment. These provisions need to be considered in conjunction with the rights of those with parental responsibility and human rights law.

In other circumstances, current case law is based on the view that persons aged under 16 years, may be competent to make decisions about their care and treatment when provided with sufficient information in a suitable format.

This is sometimes referred to as "Gillick" competence®. This principle recognises the concept of emerging capacity in children and young people. Cognitive and emotional skills are acquired differentially throughout adolescent development. Whilst decision-making is primarily dependant on information retention and processing, emotional maturity is needed to make balanced, unwavering decisions and to cope with the consequences of those decisions. It is important to assess the child or young person's maturity and understanding on an individual basis, and to remember that the severity of the consequences of the decision should be taken into account.

Steroidal therapy has been recommended on a long term basis for a 15 year old girl with asthma. The girl has voiced some reluctance to take the medication because of the possible side effects, like weight gain. The girl’s named nurse takes her to a quiet room where they can discuss the proposed treatment plan. The discussion includes information about the reasons why the plan has been proposed, the benefits in taking the medication, the possible side effects of the medication, the probability of occurrence of the side effects and the likely outcome should the girl decline the medication. The named nurse is satisfied that the girl has understood all of the information discussed. The girl has also asked appropriate questions in response to the information provided and has been able to engage fully in the conversation. Considering all of this, the nurse is confident that the girl has demonstrated an appropriate level of emotional maturity to enable her to make her own decision about taking the medication. The girl decides that she does not want to take the steroidal therapy. The nurse respects her decision and supports her to discuss other options with the multi-disciplinary team.

Gillick competent young people can consent to or refuse care, treatment and/or interventions. However, refusal to provide consent can be over-ridden by a person with parental responsibility or a court in certain circumstances. If more than one person has parental responsibility for the young person, consent by any one such person is sufficient, irrespective of the refusal of any other individual.

Where a child or young person lacks capacity to consent, consent can be given on his or her behalf by any one person with parental responsibility, or by the court. As is the case where individuals are giving consent for themselves, those giving consent on behalf of the child or young person must have the capacity to consent to the intervention in question, be acting voluntarily,

** Gillick v West Norfolk and Wisbech AHA [1986] AC 112
and be appropriately informed. The power to consent must be exercised according to the “welfare principle”: that the welfare or best interests’ of the child or young person must be paramount. Even where the child or young person lacks capacity to consent on their own behalf, they must be involved as much as possible in the decision making processes.

Where necessary the courts can, as with competent children and young people, over-rule a refusal by a person with parental responsibility. It is recommended that certain important decisions, such as sterilisation for contraceptive purposes should be referred to the courts for guidance, even if the person with parental responsibility has consented to the procedure.

Professional accountability

Professional accountability means being personally answerable to the law of the land for all actions or omissions (including what is written or is not written, what advice/information/communication is given or is not given) while fulfilling a contract as a health and social care employee.

Registered nurses must act first and foremost to care for and safeguard those in their care. Registered nurses must display a personal commitment to the standards of practice and behaviours set out in the NMC Code. NMC states that registered nurses must “show professionalism and integrity and work within recognised professional, ethical and legal frameworks” (NMC, 2015b).

It should be noted that the standards expected of registered nurses by NMC may be at times higher than the minimum required by law. Legal requirements in negligence cases have historically been based on the standards set by professional bodies for their members, and hence where standards required by professional bodies are rising, it is possible that the legal standards will rise accordingly.

Professional values and competencies required of registered nurses dictate an understanding of current relevant legislation which must be applied in all areas of practice. Where registered nurses lead teams of staff, they must ensure that all team members understand how to apply their practice legally and ethically.

Who should seek consent and when?

The registered nurse providing the treatment, investigation or care is responsible for ensuring that the person has given valid consent before the examination, treatment or care begins. If another health or social care professional has sought and received consent for an intervention, the registered nurse providing the treatment, investigation or care must be assured that valid consent has been provided and recorded before the intervention is undertaken.

A ten year old boy needs a bone marrow transplant for which his eight year old sister is a match. The parents want to proceed with a donation of bone marrow from their daughter for their son. Their daughter is too young to be able to understand the implications, effects and consequences of the procedure and cannot provide consent for the intervention. The needs of one sibling cannot be balanced against the needs of the other and the donation of the bone marrow must be considered to be in the best interests of the healthy child. Agreement cannot be reached to determine if the procedure to donate bone marrow is in the best interests of the young girl even though the transplant is essential for her brother’s survival. In these circumstances a court ruling is sought to determine if the procedure can go ahead.
Form of consent

The validity of consent does not depend on the form in which it is given. Consent can be expressed in writing, verbally or non-verbally.

A gentleman with a learning disability who does not communicate verbally needs to have a blood test. The nurse who will be undertaking the intervention uses easy to read information and pictures to demonstrate to the man that she would like him to agree to a blood test. The information also explains that it might hurt a little but not for too long. The man gives a “thumbs up” to indicate that he has understood the information. He rolls up his sleeve and extends his arm to allow the nurse to take the blood test. The nurse records details of how she provided information to the gentleman and how he provided his consent.

In most cases completion of a consent form is not a legal requirement, (exceptions being prescribed forms associated with mental health legislation (Mental Capacity Act 2005, Adults with Incapacity (Scotland) Act 2000, Mental Health (Northern Ireland) Order 1986, Mental Capacity Act (Northern Ireland) 2016) Mental Health (Scotland) Act 2015 and the Human Fertilisation and Embryology Act 1990).

Although written forms serve as evidence of consent, the completion of any consent form or documentation must meet with the requirements that constitute valid consent, ie the person has the capacity to make the decision, sufficient information has been provided to ensure that consent was “informed”, and that consent has been freely given. Where a person is illiterate or unable to fully complete their signature, but is able to provide valid consent, they may be able to make a mark on the form to indicate consent. It is good practice to have the mark witnessed by another clinician. If consent has been validly given, the lack of a completed form is no bar to treatment or care.

Duration of consent

When a person provides valid consent for an intervention, that consent remains valid for the duration of the intervention, unless withdrawn by the person during the course of the intervention.

A lady has provided written consent to undergo a course of chemotherapy following surgery for cancer. The consent form details the number of occasions on which chemotherapy will be administered and will remain valid until all treatments have been completed. The lady does not need to complete a consent form each time she attends for treatment.

After three treatments the lady decides that she does not want to complete the course of six planned treatments. The possible consequences of not completing the full course of treatment are explained to the lady. However, she maintains that she does not want to complete the course of treatment. Her decision is respected by the multi-disciplinary team and other care and treatment options are discussed.

Consent for sharing information

There is a requirement in the NMC Code (NMC, 2015a) at paragraph 5 which explicitly requires nurses to respect a person's right to privacy and confidentiality.

When a person discloses personal health information to a health or social care professional, it is generally accepted that care cannot continue unless it is shared with other staff involved in their care. This could include both health and social care staff and administrative staff. Registered nurses must ensure that implied consent to sharing of information is not assumed in these
circumstances and that any disclosure of information to others is absolutely essential for the provision and continuation of care, and in accordance with the requirements of the Data Protection Act 1998 and the Human Rights Act 1998. The duty of confidentiality applies to both adults and children and young people (as clarified in the Gillick principle).

Should the person state that they do not want information to be shared with anyone, a registered nurse has no permission to do so.

There is however a recognition that the duty of confidentiality is not absolute. In certain situations a registered nurse could be required to disclose information without the consent of the individual involved. These circumstances may exist where there is a real and serious risk of danger to the public or an identifiable individual, or in the case of a child/young person or where a person with capacity is considered vulnerable. The onus will be on the registered nurse to provide evidence that the absence of consent and a breach of confidentiality meets these specific requirements.

Finally

This document has been designed by the RCN to give registered nurses information to guide their practice. It is impossible to document every intervention or issue that a registered nurse faces in their workplace and each patient is an individual with specific needs. Following the principles of consent discussed in this document will guide registered nurses in legal, ethical and professional practice. However, where a registered nurse is unclear about any aspect of the consent process, they must discuss this with their line manager before proceeding with the treatment or intervention.
References


Nursing and Midwifery Council (2015b) Standards for competence for registered nurses 2015, London: NMC.


Gillick v West Norfolk and Wisbech AHA [1986] AC 112.


Mental Capacity Act (2005).

Mental Health (Northern Ireland) Order 1986.

Mental Health (Scotland) Act 2015.

Mental Capacity Act (Northern Ireland) 2016.


Additional sources of information

Adults with Incapacity (Scotland) Act 2000.

Age of legal capacity (Scotland) Act 1991.


