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*Consent*

*and*

*Communication*

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## *Ethical issues and Irish law*

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- Requirement is established in Irish Case Law and recognised in International and European Human Rights Law and under the Irish constitution;
- It is a basic rule in common law, that consent must be obtained for medical examination, treatment, service or investigation;
- The ethical rationale behind the importance of Consent is the need to respect the service user's right to control their own life and to decide what happens to their own body.

## *Therefore:*

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- Other than in exceptional circumstances, treating service users without their consent is a violation of their legal and constitutional rights and may result in civil or criminal proceedings being taken by the service user.

## *Age of Consent in Irish Law*

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- The Non-Fatal Offences against the Person's Act 1997 states, that persons over the age of 16 years can give consent for medical, surgical and dental procedures;
- The Child Care Act, 1991, The Children Act 2001 and The Mental Health Act 2001, defines a 'child', as a service user under the age of 18 years, "*other than a service user who is or has been married*".

## *When is Consent required?*

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- It extends to all interventions by or on behalf of the HSE on service users in all locations e.g.
  - Surgical/anaesthetic procedures;
  - Chemo/Radiotherapy/Use of blood products;
  - Adm of medication/Clinical photography etc;
  - AON for Health and Social care;
  - Provision of Social Care/Day/Residential care;
  - Psychological Interventions.

## *What is valid consent?*

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- The giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention;
- Be acting voluntarily (not under undue pressure/duress from anyone);
- Have the mental capacity to make the particular decision.

# *How much information should be given?*

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- Effective communication ensures Consent is valid - should be an on-going process, rather than a once-off event;
- The amount of information service users want and require will vary depending on individual circumstances;
- Should as much as possible be tailored to:
  - their needs, wishes, priorities;
  - their level of knowledge and understanding of their condition, treatment, prognosis and treatment options;
  - their ability to understand the information provided and language used;
  - the nature of their condition.

## *What information do people need?*

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- Amount of information will depend on urgency, complexity, nature and level of risk associated with the intervention:
  - Information on their diagnosis and prognosis;
  - Options for treating their condition including the option not to treat;
  - Purpose of the proposed treatment and what it involves;
  - The potential benefits, risks, likelihood of success as a proposed intervention as well as that of any available alternative treatment.



# *How and when should information be offered?*

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- In a respectful manner;
- Privacy....Place and at a time when service user is best able to understand and retain the information....over a number of consultations;
- Provision of adequate time and support;
- Use of simple, clear, concise language with avoidance of jargon and medical terminology;
- Supplementing with visual depictions; Use of interpreter service (not family or friends); lip reading/email/texting; large print/braille/audio information;
- Asking service user to identify anything that will help him/her to remember information/make it easier to make a decision e.g. partner, friend, advocate at consultations.

## *When can consent be legitimately abbreviated?*

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- In emergency situations.....where the intervention is immediately necessary to save the life or preserve the health of the patient;
- Where the service user declines information.....it is important that some basic information is provided, so that consent can be obtained and the service user is advised of what is involved;
- Where detailed information is refused this should be documented.

## *Note:*

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- The fact that one may be upset or refuse treatment or services as a result of receiving information as part of the consent process is not a valid reason for withholding information that they need or are entitled to know.

# *Voluntary Decision Making*

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- For consent to be valid, care should be taken that people do not feel forced into making a particular decision. They must understand that they have **CHOICE**.
  
- Duress does not refer to:
  - the pressure that the illness itself can impose on the service user;
  - strongly recommending a particular treatment or change in lifestyle activity;
  - pointing out the likely consequences of choices the service user may make on their health/treatment options.

## *Has the person the Capacity to make the decision?*

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- Adults are always presumed to have capacity to make healthcare decisions, unless the opposite has been demonstrated;
- All service users may experience temporary lack of capacity due to severe illness, loss of consciousness or other similar circumstances;
- Must not be assumed that one lacks capacity because of age, disability appearance, behaviour, medical condition (incl intellectual disability, mental illness, dementia, scores on tests of cognitive function);

# *Capacity to Consent*

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- Capacity should be assessed if there is sufficient reason to question the presumption of capacity;
- In Ireland the test is a functional one and is drawn from Case Law:
  - understands in broad terms the nature of the decision to be made at that time;
  - Has sufficient understanding of the main benefits/risks of an intervention and relevant alternative options;
  - Understands the relevance of the decision and is able to retain the knowledge long enough to make a voluntary choice.

## *Capacity to Consent contd.*

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- Capacity should not be confused with the reasonableness of, or wisdom, of the person's decision as long as they understand the consequences of that decision ...religious beliefs, value systems;
- People who lack capacity are very often able to express a preference to receive or forego a treatment. This view carries great weight.

## *What to do if service user lacks capacity*

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- The Health Professional should determine what is in the service user's best interest decided on by reference to their preferences and values if known:
  - Evidence of previously expressed preferences, wishes, beliefs;
  - Whether lack of capacity is temporary or permanent;
  - What treatment options would provide overall clinical benefit for the patient;
  - What options would be least restrictive for the patient's future choices incl option not to treat;
  - Current views of patient if ascertainable.



## *Remember!*

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- Healthcare professionals have a duty to maximise capacity....efforts must be made to support individuals in making decisions for themselves where this is possible
- No other person such as a family member, friend, carer or organisation can give or refuse consent on behalf of an adult who lacks capacity to consent unless they have formal legal authority to do so

## *Consent in Emergency Situations*

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- Where a patient is deemed to lack capacity the healthcare professional should act in the best interests of the patient
- Usually means providing necessary treatment to save life or prevent serious deterioration of the patient
- Good practice to inform those close to the patient however, no one else can consent on behalf of the patient in this situation (unless they have formal legal authority to do so)

## *Who should obtain consent?*

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- The treating Healthcare Professional is ultimately responsible for ensuring the patient consents to treatment etc;
- The task can be delegated to another suitably qualified and trained Healthcare Professional, who can provide the information the service user requires;
- Inappropriate delegation.....may mean consent obtained is not valid;
- MD treatment of a patient.....consent should be obtained by each discipline for their intervention.

## *Consent in Immunisation... Why is it required?*

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Consent acts as protection for both Health Professionals and individuals, so that if any questions are asked in the future, there is a record available to show what the individual agreed to on the day of Consent.

## *Valid Consent in immunisation...what information should be provided?*

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- What vaccines will be administered and against which disease they provide protection;
- What are the benefits and risks of immunisation and the risks of disease(s);
- What are the possible side effects of immunisation; when might they occur and how should they be treated;
- Alternatives to vaccination.

## *How is this information provided?*

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- Information leaflets;
- Discussion with administering practitioner or designate;
- Reputable health-related websites.

# *What is the Age of Consent?*

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- The Child Care Act, 1991, the Children Act 2001 and the Mental Health Act 2001 defines a “*child*” as a service user under the age of 18 years, “*other than a service user who is or has been married*”;
- Irish Law permits a person aged 16 to consent to treatment (medical, surgical, dental);
- >16 years seen to have capacity to Consent, but not necessarily the capacity to refuse.....go to court;
- For children under 16 consent is given by the parents or a legally recognised guardian.

## *How should consent be recorded?*

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- Essential that the accompanying consent form is signed before the procedure begins;
- All decisions and discussions that have taken place with the client that led to the agreement should be recorded;
- While it is important to document consent adequately, the process and quality of communication are of equal importance.



## *How should consent be recorded when the client is illiterate?*

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- If the individual giving consent is illiterate but competent they can be asked to make their mark on the consent form .....good practice that their mark is witnessed by someone other than the health professional seeking consent;
- Similarly if the individual is competent but is unable to make their mark or signature this needs to be recorded in the participant's notes and witnessed by someone other than the administering health professional....verbal consent;

## *How should consent be recorded when the client's first language is not English?*

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- Translated information leaflets;  
[www.immunisation.ie](http://www.immunisation.ie)
- Use of Translator;

# *How long does Consent remain valid?*

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- There is no legal authority to support the validity of any particular time period;
- Some services set a max. fixed time period for which consent remains valid;
- In general, if there is a significant time lapse between seeking and giving of consent i.e. person unable to recall info given previously, if patient's condition has changed or if there is new information available on the intervention, then a fresh consent should be obtained;
- Consent can be withdrawn at any time.....good practice to establish the concerns and explain the consequences of their decision.

# *Who can give consent for children?*

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- Under Irish Law the following rules apply:
  - Where parents are married, both parents are legal guardians;
  - The mother has automatic parental responsibility/legal guardianship. The father is also given parental responsibility if he is married to the mother at the time of the child's birth or if they marry after the birth of the child;
  - If both adults adopt the child together, the adoptive parents are both legal guardians;
  - After separation or divorce both parents remain legal guardians;
  - If the parents are not married, the child's mother is the only automatic legal guardian. The child's father may also be legal guardian by agreement with the mother effected by way of a statutory declaration or by a Court Order.

## *Is Consent necessary from both parents?*

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- Seeking the consent of one parent is widely accepted as sufficient in the Health Service within Ireland and in other jurisdictions ....more practical for safe, timely and effective service provision in the interests of the child;
- Where both parents have clearly indicated their wish to be involved in decision-making, this must be accommodated as far as possible by the service provider;
- Where parents are in dispute, withhold treatment. May be necessary to seek court approval.

## *Phone Consent?*

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- Where a child is accompanied by a grandparent/babysitter who does not have legal authority to give consent for the child, consent can be obtained by phone if the parent is unable to attend. This must be documented;
- The same standard of informed consent described above applies.

## *Consent where the child's parent is a minor*

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- A minor is defined as a person who is less than 18 years who is not, or has not been married;
- Presumed to be the best decision-maker for their child;
- If their decision is considered not to be in the best interest of their child, their decision should be discussed with them;
- If appropriate and with the consent of the minor parent another person(s) e.g. grandparent(s) may be involved;
- No agreement in life threatening situation...legal advice should be sought;

## *Consent for Children In Care*

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- Child Care (Amendment) Act 2007 updates the Child Care Act 1991;
- It is the responsibility of TUSLA to ensure that there is an appropriate care order in place for a child where consent is required;
- Voluntary care...child's parent/legal guardian unless court order has been made dispensing with that person's consent;
- No parent/legal guardian...application by TUSLA to District Court(Section 47 CC Act 1991) authorising TUSLA to give consent;



## *Consent for Children in Care*

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- Children subject to Interim and Emergency Care Orders.....application to District court...TUSLA (Area Manager)authorised to give consent;
- Children subject to Full care Order....TUSLA authorised (Section 18 of CCA1991) to consent for any necessary medical/psychiatric interventions....Good practice to seek consent of parent/legal guardian;
- The child's parent/legal guardian may still have a legal entitlement to give consent where they are contactable and cooperative with medical/nursing personnel but the child's interest are, as always, the paramount consideration.

## *Consent for Foster Children*

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- Foster child (< 5years in placement)...Child's parent/legal guardian...application to District court (Section 43A) authorising TUSLA to give consent;
- Foster care for( > 5years).....a foster carer/relative, with the consent of TUSLA, can apply and be granted an Order (Section 43A CCA 1991) giving them like control over the child as if they were the child's parent/legal guardian;
- Therefore, for a child who is <16 years of age and in foster care for <5years, the consent of the child's natural parent(s) and of TUSLA is normally required.

## *Confidentiality...Should I tell the parents?*

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- Confidentiality is the cornerstone of medical ethics and fundamental to the trust between you and your patient;
- Essential that young person is not deterred from seeking treatment for fear of disclosure to parents;
- In medical ethics and law it is justifiable to disclose if you conclude that the disclosure is necessary to prevent harm to the patient or to someone else;
- Best practice to advise the patient that you intend to make such a disclosure.

## *Underage sexual activity...should I tell?*

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- Under Irish law it is a criminal offence to engage or attempt to engage in a sexual act with a child under 17 years of age;
- No provision in law regarding the age, at which contraceptive advice, treatment, sexual health services can be provided...therefore a person >16 years can give their own consent to contraceptive/sexual health advice or interventions.

## *Remember!*

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- In light of possibility that sexual activity with a child <17 years may constitute a criminal offence, efforts should be made to involve the parents/legal guardians in the consultation and decision-making;
- Critical in this situation that health professional rules out any possibility/suspicion of abuse, exploitation or non-consensual sexual activity.

## *Therefore!*

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- Document the result of an assessment to see if there is suspicion or evidence of abuse;
- Document the actions taken;
- Document efforts made to encourage the minor to involve his/her parent(s)/legal guardian(s);
- Be aware of the requirements under Children First Guidelines(2011) to report underage sexual activity to TUSLA.

# *Confidentiality and Data Protection*

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- Service users have a right to expect their info is held in confidence by those providing care....confidentiality is central to trust;
- Staff must comply with Data Protection Acts 1988 and 2003...personal info for purposes of treatment/service provision not disclosed to third party without consent of service user;
- Complaint by family member....must have service user consent for release of personal info for internal investigation/review;
- Audit/Quality assurance programmes .....consent not usually sought except where identifiable data is made available to a third party;
- Good practice to inform service users that such practices occur and that safeguards exist to ensure their personal data is protected.

# Thank you

## ■ *Useful resources*

- Data Protection Commissioner (Ireland) [www.dataprotection.ie/viewdoc.asp?DocID=4](http://www.dataprotection.ie/viewdoc.asp?DocID=4)
- Department of Health and Children. Consent to medical and surgical procedures.
- [www.dohc.ie/public/information/legal\\_matters\\_and\\_health/consent\\_to\\_medical\\_and\\_surgical\\_procedures.html](http://www.dohc.ie/public/information/legal_matters_and_health/consent_to_medical_and_surgical_procedures.html)
- Irish Statute Book. Guardianship of infants act, 1964.
- [www.irishstatutebook.ie/1964/en/act/pub/0007/index.html](http://www.irishstatutebook.ie/1964/en/act/pub/0007/index.html)
- National General Practice Information Technology Group (GPIT) Ireland  
[www.gpit.ie/patient\\_consent.html](http://www.gpit.ie/patient_consent.html)
- NHS. Department of Health. Consent – What you have the right to expect. 2005
- [www.dh.gov.uk/policyandguidance/healthandsocialcaretopics/consent/consentgeneralinformation/fs/en](http://www.dh.gov.uk/policyandguidance/healthandsocialcaretopics/consent/consentgeneralinformation/fs/en).
- Royal College of Nursing (UK). Informed consent in health and social care research (2001) available from:  
[www.rcn.org.uk/publications/pdf/informed\\_consent\\_in\\_health\\_and\\_social\\_care\\_research.pdf](http://www.rcn.org.uk/publications/pdf/informed_consent_in_health_and_social_care_research.pdf)
- The Office for Health Gain. (2000) Meningococcal C vaccine. Guidelines for practitioners including standards of good practice.
- World Health Organisation. Research ethics review committee. The process of seeking informed consent. (2004) [www.who.int/rpc/research\\_ethics/Process\\_seeking\\_IF\\_printing.pdf](http://www.who.int/rpc/research_ethics/Process_seeking_IF_printing.pdf)
- HSE National Consent Policy2013; [www.hse.ie](http://www.hse.ie)