

HSE Strategy and Research

HSE National Office for Human Rights and Equality Policy Newsletter

Launch of HSE National Consent Policy 2022

Spring 2022



National Office for Human Rights and Equality Policy



The National Consent Policy 2022 is being launched on Monday 28th March 2022. The new policy revises the National Consent Policy which was developed in 2013.

In this newsletter the co-chairs of the HSE National Consent Policy Steering Group tell us about the main changes in the revised policy. We hear from a number of people who describe why consent matters to them as people who use health services and as front-line practitioners.

The policy will be available following the launch from www.hse.ie/nationalconsentpolicy. The E-Learning programme to support the policy will also be available following the launch for those who have access to HSEland– www.hseland.ie.

A series of recorded webinars on consent, capacity and supporting decision making are already available on www.assisteddecisionmaking.ie as a resource for staff.

Concerted efforts are now underway to support commencement of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) in June 2022. The revised HSE National Consent Policy 2022 has been written in a way to take account of the general principles in the 2015 Act. The policy will require further amendments in June 2022 when the Act is fully commenced.

The newsletter details ongoing work to support preparations for the commencement of the Assisted Decision-Making (Capacity) Act 2015. It also provides an extensive list of resources for staff to support your practice.

Further details on plans to support the HSE to prepare for commencement will be in our next newsletter and is available on www.assisteddecisionmaking.ie.

If you have any questions on the revised National Consent Policy feel free to get in touch with us at adm@hse.ie.

Caoimhe Gleeson, Programme Manager
HSE National Office for Human Rights and Equality Policy

National Office for Human Rights and Equality Policy Update

HSE National Consent Policy

The HSE National Office for Human Rights and Equality Policy and the HSE National Consent Policy Steering Group have been working on an extensive revision of Parts 1 and 2 of the HSE National Consent Policy 2013 (revised 2019) bring it in line with policy and legislative changes since 2013 and to reflect to recent case law.

The revised policy does not amend Part Three (Research) or Part Four (DNAR) of the 2013 (revised 2019) HSE National Consent Policy. Until a new policy is developed for Research and DNAR the existing Part 3 and Part 4 and the HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic will be attached to this policy.

The revised HSE National Consent Policy and supporting e-learning programme will be launched on **Monday 28th March 2022 at 10.30 a.m.** Please click into the below link to register for the event:

https://zoom.us/webinar/register/WN_WPrZ7euzRPW04sICcuiNrg

Launch of E-Learning Programme- Supporting Decision Making in Health and Social Care

The launch will take place of the E-learning programme on Supporting Decision Making in Health and Social care on **April 7th at 2pm**. This programme includes three modules which are supporting decision-making, planning for the future and the functional assessment of capacity. Details of the launch will be disseminated in the coming weeks. Please click the following link to register for the event: https://zoom.us/webinar/register/WN_pU-WhtEuT-OcTRy_J8egPQ

Further information and materials to support staff to prepare for commencement of the Act will be uploaded to the website www.assisteddecisionmaking.ie over the next few months.

Webinar series 2022

As part of the ongoing preparation for commencement of the Assisted Decision-Making (Capacity) Act you would like to get in touch with us about this please email adm@hse.ie.

Webinar Series 2022 – Assisted Decision-Making (Capacity) Act 2015- Preparation for Commencement and Implementation

The first webinar in this series took place on Wednesday 16th February 2022 and focused on decision support arrangements under the Assisted Decision-Making (Capacity) Act 2015. The webinar recording is available on www.assisteddecisionmaking.ie. The second webinar

held on the 22nd March on How and when to engage with the Decision Support Service recording will also be available on www.assisteddecisionmaking.ie.

The remaining webinar topics in this series are as follows:

27th April – Positive risk-taking and unwise decisions

May – Functional assessment of capacity

June - Respecting the rights of the person/ The role of families under the 2015 Act.

Notification of the webinars will be disseminated to the HSE National Office for Human Rights and Equality Policy mailing list, through the members of the ADM Implementation Steering Group and through the HSE Health Service News email.



Professor Mary Donnelly & Professor Shaun O’Keeffe: ‘General principles,’ ‘Children and young people’ and what has changed.’

The HSE published its first National Consent Policy in 2013 which was based on two years of work and extensive national consultation.

A revised HSE National Consent Policy will be launched in March 2022 and represents an extensive revision and rewriting of Parts 1 (dealing with the general principles of consent as they apply to adults) and Part 2 (dealing with children and young people) of the 2013 policy. (Until planned new policies are developed relating to research and DNAR, the existing parts 3 and 4 of the 2013 policy will remain in effect).



It is important to note that the core principles underpinning valid informed consent and good practice, and the emphasis on supporting people and on good and effective communication, are unchanged.

There are a number of changes to reflect recent and forthcoming legislative and policy changes since 2013.



- Although the revised policy is based on the law as it stands, the language – in particular, an emphasis on the importance of the will and preference of a person who may lack capacity – has been changed in preparation for the Assisted Decision-Making (Capacity) Act 2015 (ADM) which is scheduled to commence in June 2022.
- The section regarding Wards of Court has been updated in accordance with new guidance from the High Court and the Office of the Wards of Court. (The current Wards of Court system will be abolished when the ADM Act is commenced).
- There is a new section on “Detention of a person contrary to their will and preference”. This reflects an important decision of the Supreme Court in the “AC case” (AC v Hickey & Ors [2019] IR 73).
- The 2022 policy retains the position that the age of consent to medical, surgical and dental treatment is 16 years. This is underpinned by extensive consultation with relevant stakeholders as to the appropriate position to adopt. It is recognised that the legal basis for this has not been definitively established in the Irish courts. However, since the adoption of the HSE National Consent Policy, this position has not been subject to legal challenge.
- The 2022 policy now states clearly that the age of consent to psychiatric treatment is 16 years, except where the child or young person has been admitted under the Mental Health Act 2001.
- Part Two of the 2022 policy reflects the increased significance of a children’s rights approach following the introduction of Art. 42A into the Constitution of Ireland and the comments of the Supreme Court in *Re JJ* [2021] IESC 1. This approach puts the best interests of the child at the core of the consent process.
- Part Two clarifies the way in which telephone consent should be obtained and recorded (where a legal guardian/s cannot be present in person).
- Part Two sets out new guidance on consent to vaccination, stating that the consent of one legal guardian will generally suffice (although also recognising that if one legal guardian has communicated an objection to vaccination, the vaccination should not proceed).

Professor Mary Donnelly, School of Law, University College Cork.

Professor Shaun O’Keeffe, MD FRCPI, Consultant Geriatrician and Physician, University Hospital Galway.

'Why consent matters in health and social care practice'

Caroline Howorth

Health and social care practice is a dynamic, interactive process - based on trust, respect and mutually shared aims. It is a collaboration, sometimes between two individuals and sometimes involving a team(s) with multiple users of service. All health and social care processes are underpinned by ethical standards - justice, autonomy, benevolence, non-malevolence and self-determination. Informed consent is a cornerstone in assuring these standards are upheld.



A health and social care partnership is an evolving process. And so it follows that consent is an ongoing process too. This is a key principle in the revised HSE National Consent Policy. That consent is not the once off signing of a form but a regular engagement between HSCPs and the user of the service to ensure each person is facilitated to guide and make decisions related to their care.

Widespread understanding and implementation of ongoing consent processes is essential to the delivery of user-led and transparent health and social care practice. It provides people with the opportunity to meaningfully engage with their service delivery. It also realises the right to question, redirect and refuse supports and interventions. Consent frames the beginning, middle and end of all our practice. From point of referral, across any transition in supports, to point of discharge. Meaningful consent processes take time at both an individual and service/ organisational level. The guidance in the revised HSE National Consent Policy will lead us to review, develop and enhance existing consent procedures across many settings – and there may be challenges along the way. But in achieving this, we will ensure that goals, supports and interventions truly are collaboratively set – enabling us to achieve the best outcomes for the patients and people we support.

Caroline Howorth, Director of Adult Clinical Services, St. Michael's House

Tony Ward : Why Consent Matters to me

Where consent is not appropriately sought from a person, service user, customer or patient it is usually because the other person has made an assumption as to that person's ability to choose for themselves and such assumptions are often badly flawed.

Aside from the disability or other reason the lack of ability to give consent may have been presumed, it is actually mostly quite rude and demeaning not to start with a presumption that a person can give consent. I am blind, but if people speak to me they will quickly find out I have complete ability to make my own decisions, yet it has often happened to me that someone I was with was asked – an example often quoted for blind people is 'does he take sugar on his tea'!



For me it is about not making assumptions in a negative way. There are services available for people who need assistance making decisions and that is fine, but for everyone else, unless a reason to the contrary, please assume that they have the capacity to make their own decisions.

Tony Ward, Chartered Accountant

The National Consent Policy: the Importance of Consent in Clinical Practice: Dr. Siobhán NiBhriain

Consent, the giving of permission or agreement for a treatment, investigation or use of a service, forms an integral part of clinical practice and the clinician-patient relationship. Consent can be a once-off interaction, for example, the taking of a blood test, or can be a complex series of interactions between clinicians and patients as a patient makes their journey through the healthcare system. Whether implied (the patients actions indicate that they are happy to go ahead with that blood test by rolling up their sleeve) or explicit (saying or signing a form agreeing to an intervention/investigation), consent should always be sought by explaining the nature of and reason for any treatment/investigation etc.

Sharing information with patients in order to seek their consent enables them to make a more informed decision about their health and treatment and for those attending services on a more long-term basis, helps them to learn more about their condition.

As the direction of healthcare moves towards a culture of empowering patients to manage their own health and well-being and including patients and service users in the development of healthcare policy, using the principles of consent enables the persons understanding of healthcare in general. Part of the process of consent includes advising on the options available, the pros and cons of various approaches, e.g. pharmacological and/or non-pharmacological treatment for certain conditions and enabling people to make informed choices. It also includes opportunities to check and re-check that the patient is happy with the planned approach.



There is a substantial body of evidence to show that those who are frightened, in pain or very anxious don't take in all the information given to them in a consultation. There are many ways of supporting the consent process by providing information leaflets that can give general information about the services people are attending or more specific information about conditions/treatments. There are many other ways of providing helpful information-screens in waiting areas, trusted healthcare websites etc.

For the vast majority of clinicians, seeking consent in various formats-by explaining treatment, by asking someone for their permission to proceed with an intervention/investigation and talking them through it, is an integral part of their clinical practice. It increases their understanding of the persons needs and puts context on the decisions they make. It is also a great enhancer of trust between individual clinicians and their patients. Consent doesn't require the use of highly technical information or language, rather it is about ensuring the patient is given sufficient information to inform their decision-making.

Studies and surveys have repeatedly shown that health professionals are amongst the most trusted in the world. In Ireland, a recent Ipsos MRBI poll showed pharmacists, nurses and doctors, in that order, are the three most trusted professions, all receiving trust scores well in excess of 90%.

That trust is something for healthcare professionals to cherish and to nourish and the National Consent Policy 2021, through its articulation of the importance of consent, is an important tool in the cannon of all clinicians.

Dr. Siobhán NiBhriain, Consultant Psychiatrist and National Clinical Director, Integrated Care, HSE.

Dr. Barry Lyons: 'Importance of consent for the child and young persons'

The UN Convention on the Rights of the Child takes a holistic approach to articulating the rights of children – setting out those aimed at promoting the inherent dignity of the child and their full physical, psychological and emotional development, alongside rights aimed at protecting children from harm. While the different rights interact with one another in a non-hierarchical and integrated way, special emphasis is given to four articles (“general principles”), three of which are essential considerations in respect of consent:



- Article 3: that the best interests of the child must be a primary consideration in all actions concerning children;
- Article 12: that the child’s views must be considered and taken into account in all matters affecting him or her;
- Article 2: that all the rights guaranteed by the Convention must be available to all children without discrimination of any kind.

Consent to healthcare processes or interventions is often regarded as an essential legal or bureaucratic requirement before these procedures can take place. For children and young persons (CYP) this means securing the agreement of their parent/legal guardian, or that of the Young Person (if they are over 16 years old), sometimes in written form. There are procedural aspects to consent including information provision, understanding and non-coercion that are as important in respect of CYP as they are for adults.

But consent in CYP requires more than an adherence to legal standards – it demands that proper attention is paid to the rights of the child. Where possible children should be encouraged to be active partners in decisions about their health and care. The evidence from CYP is that this does not always happen:

- they often experience less than optimal communication;
- when HCPs do speak to CYP they often use terms that are not understood;
- even older CYP may be relegated to a non-participant status in consultations, with information-giving solely directed at the parent;
- the information that CYP provide, and the preferences that they express, are commonly ignored;
- sometimes CYP are completely left out from discussions.

On the other hand, research indicates that children’s full participation may lead to significant benefits. It:

- allows children to feel more in control, improving their adjustment to health and social care, and to their feeling valued;
- improves their provision of clinical and social information, and acceptance of interventions;
- provides an opportunity to express feelings, and develop confidence and competence;
- reduces their fears.

Consent to health and social care interventions is a legal necessity prior to the provision of services to CYP. Respecting their rights to the greatest extent possible should be an essential part of this process. It should hardly need to be said that all children’s rights equally apply to CYP with a disability.

Dr. Barry Lyons, Consultant Department of Anaesthesia and Critical Care Medicine, Children’s Health Ireland, Crumlin.

‘Consent: Perspectives from the State Claims Agency’ - Mary Godfrey

Informed consent refers to a process whereby the patient or service user and healthcare practitioner engage in a dialogue about proposed treatment or intervention including the benefits, risks and alternatives.¹ It is an ongoing process as opposed to merely the signing of a form at a specific point in time.

The State Claims Agency (SCA) analyses both claims and incidents reported on the National Incident Management System (NIMS). Examples of incidents related to communication include patients arriving to theatre without a signed consent form or where a different or additional procedure is undertaken, for which the patient had not provided consent.



Claims rarely arise due to one single error; more usually several factors can contribute. However, analysis of clinical claims by the SCA shows that deficiencies in the communication process frequently feature in claims’ causation analysis. In a review of claims finalised by the Agency in 2017, substandard or omitted consent was one of the most significant communication deficits identified, featuring in 31% of perioperative claims and 65% of claims in the community. Although all procedures carry the risk of complications, claims may arise if the plaintiff alleges that they were not made aware of a potential complication, or if there is insufficient documented evidence of consent.

Consent may also be a factor, in the analysis of the causation of a claim, if it was obtained by a junior member of staff who was neither familiar with (due to inexperience) nor involved in the procedure. The importance of the consent process cannot be over-emphasised and the SCA believes that getting it right can mitigate the risk of incidents and claims arising.

The consent process should include the documentation of all discussions regarding the risks, benefits and alternatives of treatments and interventions. The SCA welcomes and endorses the HSE’s National Consent Policy (2022) and advises that the consent process should be carried out in line with the Policy.

Mary Godfrey, Senior Clinical Risk Manager, State Claims Agency

Footnote: Cordasco K.M. (2013) Obtaining informed consent from patients: brief update review. In *Making health care safer II: An update critical analysis of the evidence for patient safety practices*. 3, 461-470. Evidence Report/Technology Assessment. Number 211. Available from: https://www.ncbi.nlm.nih.gov/books/NBK133363/pdf/Bookshelf_NBK133363.pdf



The importance of Consent in Nursing & Midwifery and Acute Services.

Dr Karn Cliffe

The first principle of The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives cites:

“Nurses and midwives respect each person’s right to self-determination as a basic human right. In respecting the right to self-determination, the requirement of informed consent is key. Except in exceptional circumstances, it is a violation of patients’ rights to treat them without their consent. It is presumed that all adults have capacity to make healthcare decisions. Capacity is understood as the ability to understand, deliberate and communicate a choice in relation to a particular healthcare decision at a particular time (NMBI 2021)”.

Informed consent, essentially a legal principle, is designed to protect the rights of patients. Not only does this protect the patients who are central to our values but it protects us as professionals. Regardless of our own views, and while an intervention may be perceived to be in their best interest, nurses and midwives must respect patients’ decisions to consent to or decline interventions or partake or refuse to partake in research studies.

Informed consent is a term that is often talked about liberally but the intricacies of it are often misrepresented. In order to attain true consent the following requirements must be satisfied:

- A complete explanation of the intervention or care being suggested
- Possible risks or discomforts
- Description of the expected benefits
- Alternative procedures that may be available and or of benefit
- Allowing time for the patient to ask questions
- Enforcing the premise that the patient may refuse or withdraw at any time
- The person has the right to a obtain legal and medical advice
- The ascertainment that the person has capacity to understand what is being explained prior to giving consent (Wallace 1995).



Furthermore having consent as a key principle by which to deliver nursing/midwifery care enhances public trust in the professions; trust being another fundamental professional value, which we appreciate is key to enabling the delivery of high quality care. A survey by Ipsos MRBI published in the Irish Times January 2019 showed that nurses were the most trusted of all the professions, with 95 per cent of the public saying that they would trust them to tell the truth. This trust has been earned through due diligence and respect for patients’ autonomy and something we are not likely to take for granted.

By disregarding the values of consent we bring our profession into disrepute, lose the well-earned trust of our patients and their families and oppose one of the principles of the Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives. Consent is key for the delivery of care to those who entrust their lives to us every day. It keeps our patients safe and the nursing and midwifery profession beyond reproach.

Dr. Karn Cliffe, Director of Nursing & Midwifery, Dublin Midlands Hospital Group

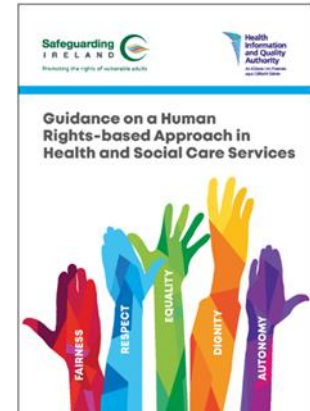


Update from HIQA

The Health Information and Quality Authority (HIQA) has developed a number of resources to help health and social care staff understand and apply a human rights-based approach to care and support in their work.

Guidance:

[Guidance on a Human Rights-based Approach in Health and Social Care Services](#) was published in 2019 in conjunction with Safeguarding Ireland. It outlines ways of working to assist health and social care staff to uphold human rights in their work.



E-learning course:

Applying a Human Rights-Based Approach in Health and Social Care: Putting National Standards into Practice e-learning course is available on HSELand.

The course consists of four modules:

- Module 1: Introduction to Human Rights in Health and Social Care
- Module 2: Role of Good Communication in upholding Human Rights
- Module 3: Putting People at the Centre of Decision-making
- Module 4: Positive Risk-taking



The modules are interactive and prompt reflection on your practice and how to incorporate a human rights-based approach going forward. Each module can be completed separately and you will receive a certificate of completion at the end of each module. There were 46,029 module completions in 2021. 99% of people who gave feedback on the modules said the modules had given them a better understanding of the topic, and 96% would recommend them to a colleague.

Additional resources:

Other resources to help you to understand and implement a human rights-based approach are available on HIQA's website [here](#), such as a FAQ, academic slide-deck, decision-making aids, and explanatory videos.

Useful resources

A number of organisations have a number of useful resources available on the Assisted Decision-Making (Capacity) Act 2015.

HSE Assisted Decision-Making website – www.assisteddecisionmaking.ie

HSE Explainer video on the Act - <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/assisteddecisionmaking/assisted-decision-act-explainer-video.html>

Decision Support Service - <https://decisionsupportservice.ie/>

Aine Flynn, Director of the Decision Support Service: Statement to the Joint Oireachtas Committee on Disability Matters May 2021 - <https://decisionsupportservice.ie/sites/default/files/2021-05/Statement-to-Joint-Oireachtas-Committee-20.05.2021%20FINAL%20.pdf>

Decision Support Service Explainer Video - <https://decisionsupportservice.ie/news-events/decision-support-service-explainer-video>

Sage Advocacy Decision-Making and Capacity - <https://www.sageadvocacy.ie/resources/legal-rights/decision-making-capacity>

Inclusion Ireland Assisted Decision-Making - <https://inclusionireland.ie/assisted-decision-making/>

Inclusion Ireland Easy to Read Assisted Decision-Making (Capacity) Act 2015 - <https://inclusionireland.ie/wp-content/uploads/2020/11/ETR-ADM-Updated.pdf>

Decision Support Services guides and video presentations - <https://www.decisionsupportservice.ie/news-events/dss-launches-simple-guides-and-video-presentations>



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