



# QI TALK TIME

Building an Irish Network of Quality Improvers

**The Assisted Decision Making (Capacity) Act 2015- what is it and what does it mean for practice?**

**Tuesday 14th May 13.00 - 14.00  
2019**

**Connect**

**Improve**

**Innovate**

# Speaker

**Caoimhe Gleeson** is the National Programme Lead for Assisted Decision Making in the HSE established to prepare staff and services for the commencement of the Assisted Decision Making (Capacity) Act 2015. This includes the development of the Code of Practice on the 2015 Act for health and social care staff, drafting of the Codes on Advance Healthcare Directives on behalf of the Minister for Health, assessing the impact the 2015 Act will have on health and social care staff and service delivery, and the development of a suite of education and training tools. She is National Specialist in Accessibility and has worked in the area of equality and human rights advocacy, service user partnership and policy.

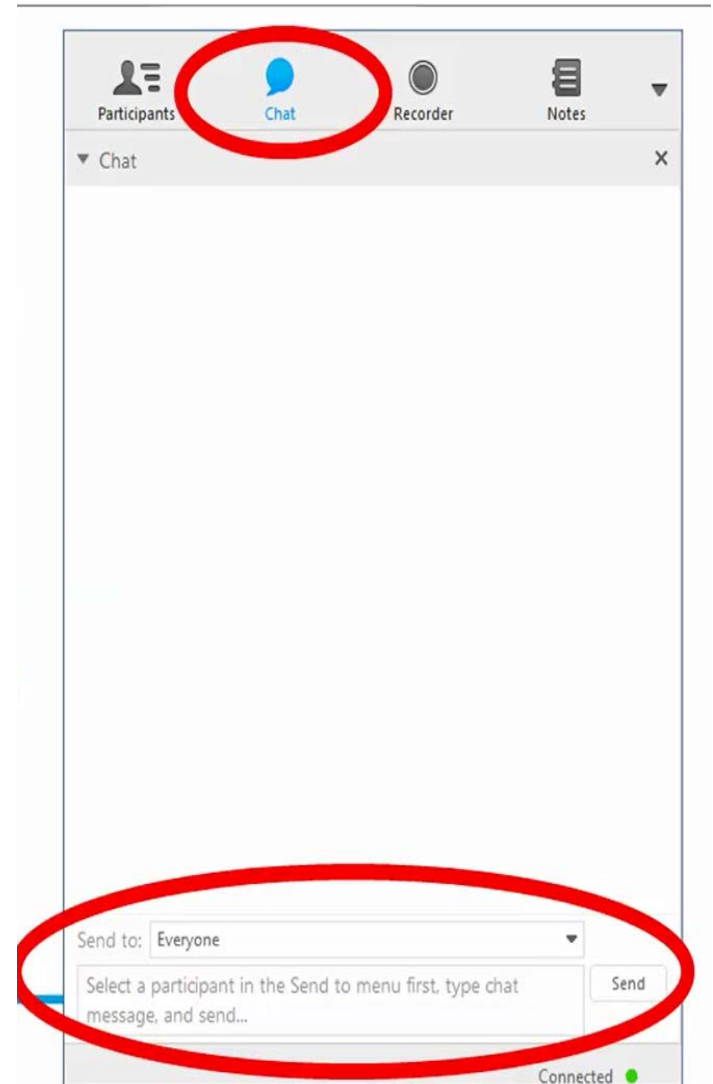
Before the H.S.E. she worked in Community Development with NUI, Galway in partnership with a wide variety of agencies and non-governmental organisations on programmes relating to gender equality, youth work, intercultural education, conflict transformation and mediation, development of civil society and citizenship rights in El Salvador, Ghana, United States, Mongolia, Croatia and Bosnia-Herzegovina.

She holds a Master's Degree in Community Development, a Professional Diploma in Equality and Human Rights, is an accredited mediator and qualified psychotherapist.



# Instructions

- Interactive
- Sound:  
Computer or dial in:  
**Telephone no: 01-5260058**  
**Event number: 846 710 368 #**
- Chat box function
  - Comments/Ideas
  - Questions
- Keep the questions coming
- **Twitter: @QITalktime**



# Assisted Decision-Making (Capacity) Act 2015

What it is and what does it mean for practice?



Caoimhe Gleeson

ADM and Consent Programme Lead /  
National Specialist in Accessibility

# What this webinar will cover?

- Explainer video
- About the Act
- What does the Act mean for your practice?
- Information on the role of the Decision Support Service
- Role and Function of the HSE National Assisted Decision-Making and Consent Office

# Key components of the Act

- Functional approach to decision-making capacity
- Establishment of the Decision Support Service
- Revision of the Enduring Power of Attorney system
- Advance Healthcare Directives
- Legally recognised persons
  - Decision-Making Assistant, Co-Decision-Maker, Decision-Making Representative
  - Enduring Power of Attorney, Designated Healthcare Representative
- Abolition of the Wardship system

# What is capacity?

Capacity is defined as the person's ability to understand, at the time a decision is to be made, the nature and consequences of the to be made by him or her, in the context of the available choices at that time.



# Functional approach to capacity

- Focusses on how the decision is made, not the outcome or consequence of the decision
- Functional approach is issue specific, context specific and time specific

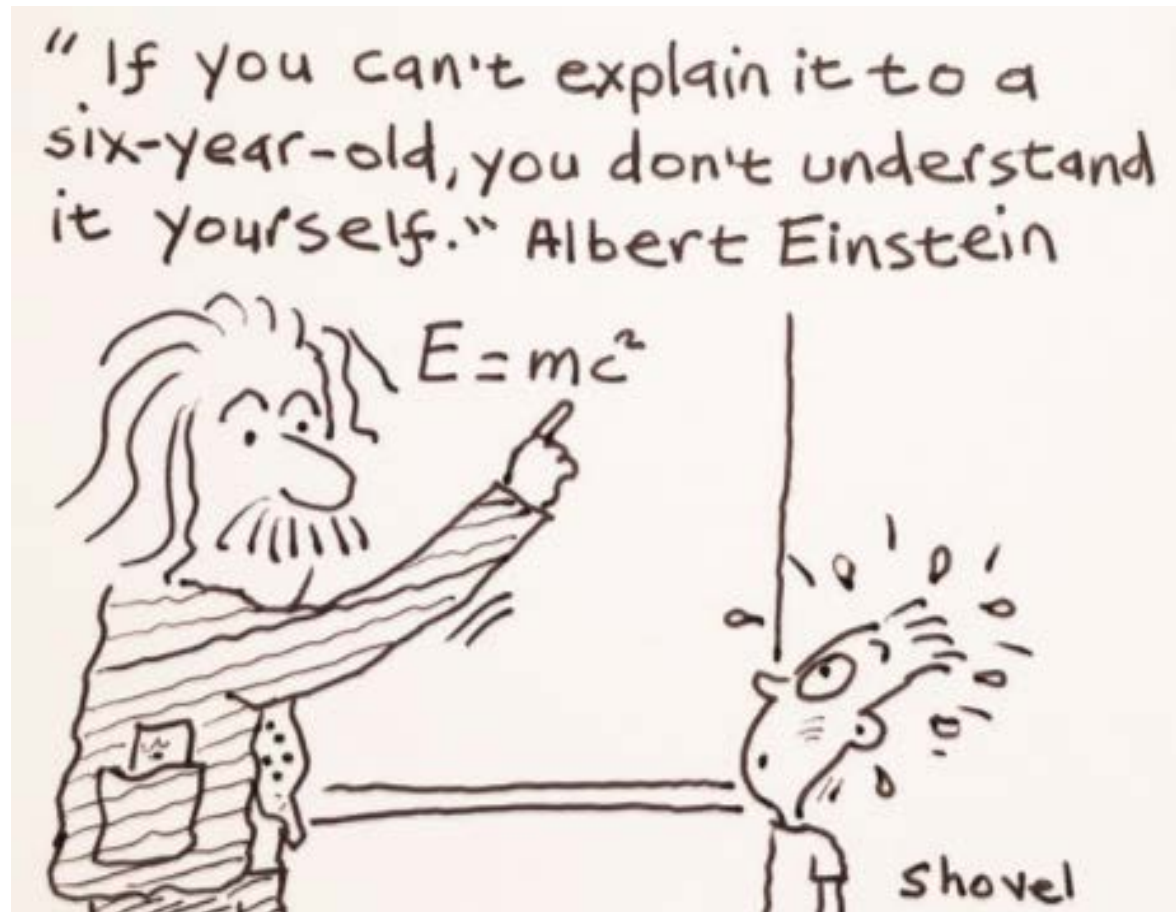




# **Functional approach to capacity**

The functional approach states that a person is unable to make a decision for himself if he is unable:

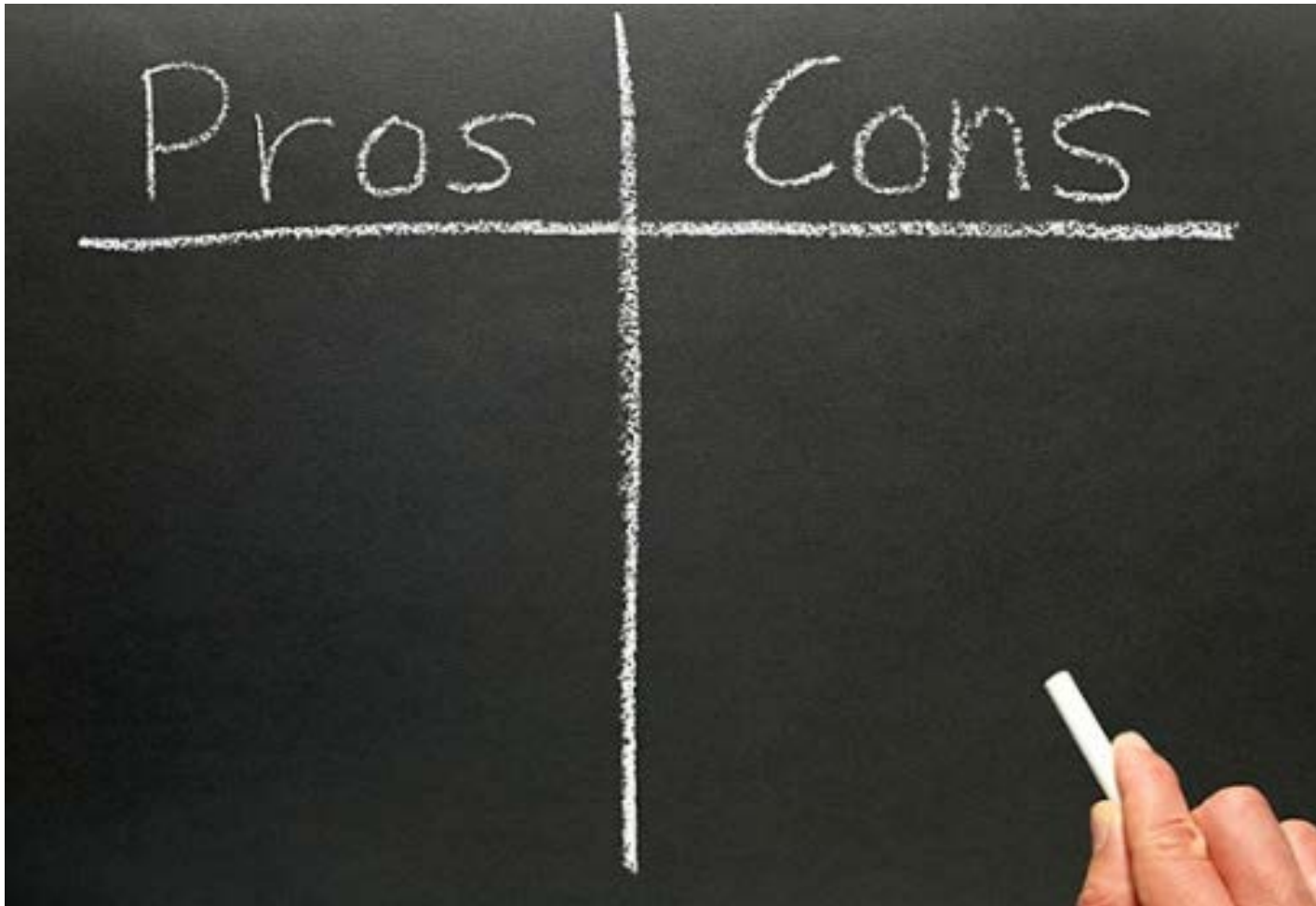
To understand the information relevant to the decision;



To retain that information for long enough to make a choice;



To use or weigh that information as part of the process of making the decision; or



To communicate their decision (whether by talking, sign language, using technology or any other means)



# Will and preference

If there is concern that someone lacks capacity to make a decision, it is essential that their past **will and preferences** are taken into consideration



"He'll take a dozen long-stemmed roses."

# Will and preference

- A person's "will" is used to describe a person's long-term vision of what constitutes a "good life" and fulfilling life for them.
- A person's "preference" means his or her greater liking for one alternative or another over others which can be, or has been, demonstrated by words or behaviour or both.

# Need to consider

- What they would have wanted to happen before they lost capacity
- Their beliefs and values



"Mum says she wants to stay in her own home, but failing that, she'll settle for a villa in Spain."



IN YOUR  
BEST  
INTEREST

IN YOUR  
BEST  
INTEREST

IN YOUR BEST  
INTEREST



# Legally recognised persons

The Act provides for legally recognised persons referred to as ‘interveners’ to support a person to maximise their decision making capacity



[intervention, Intervention, get  
involved, intervener]

# Legally recognised persons

- Decision-Making Assistant
- Co-Decision-Maker
- Decision-Making Representative
- Enduring Power of Attorney
- Designated Healthcare Representative



# Legally recognised persons

- **Appointment by person with Capacity to plan for the future – comes into effect when person lacks capacity**
  - Attorney: Enduring Power of Attorney
  - Designated Healthcare Representative: Advance Healthcare Directive
- **Appointment by person when Capacity is in question/shortly in question**
  - Decision-Making Assistant: Decision-Making Assistance Agreement
  - Co-Decision-Maker: Co-Decision-Making Agreement
- **Appointment by Court when person lacks capacity – EPA or AHD does not include decision to be made**
  - Decision-Making Representative: Decision-Making Representation Order

# Advance Healthcare Directives

- Comes into effect when the directive-maker lacks capacity
- Person can refuse medical treatment in advance
- Person can request medical treatment in advance- not legally binding



# Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is an arrangement whereby a **Donor** (the person who may **lack capacity in the future**) gives a general power to an **Attorney** (the person providing assistance) to act on their behalf.





**IMPLICATIONS**

# Are we ready for will and preference?





# The challenge of will and preference

- 55,000 people with a dementia diagnosis
- Projected to double in the next 20 years
- No statutory right to home care
- Nursing home admission in Ireland- twice the EU average
- Average home support package- \*15-21 hours per week- 168 hours in the week

# **Recalibration of policy for services for older people?**



# What about disability services?

- 2012- 3,391 people living in congregated settings
- 2017- 2,370 people (30% reduction)
- Planned move 2019- 160 people
- 28 years- average time that people have lived in the congregated settings
- Average age is 52
- Challenges- Housing market, Limited Capital Programme

# Raised expectations

- Can we honestly honour will and preference?
- Is it a Postcode lottery?
- “There have been a significant number of people who have died and most have traded one institution for another with a move into nursing homes or other institutions. It is also worth noting that a national policy of no new admissions to institutions has not been put in place”, **Paddy Connolly, Former CEO, Inclusion Ireland**

# Risk, safety and liability



# Unwise decisions

An unwise decision does not indicate a lack of capacity



# What is risk?

Risk is the likelihood of a hazard causing harm





# What happens when will and preference is no longer safe?



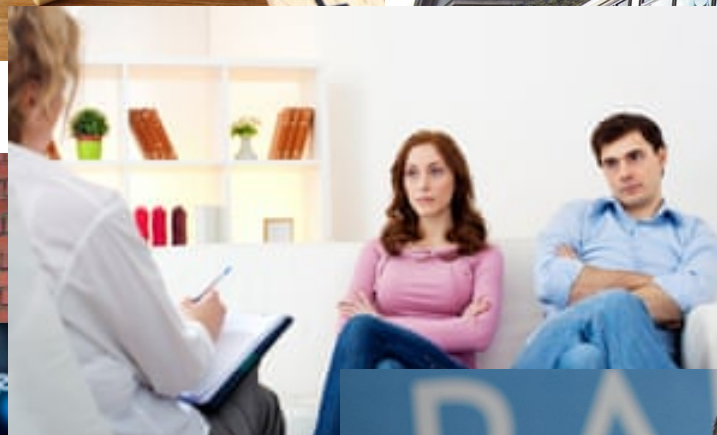
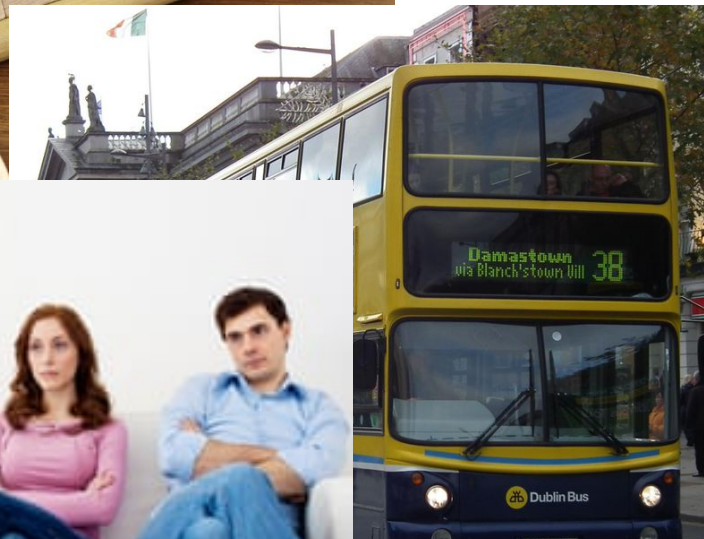




# Key concerns of staff

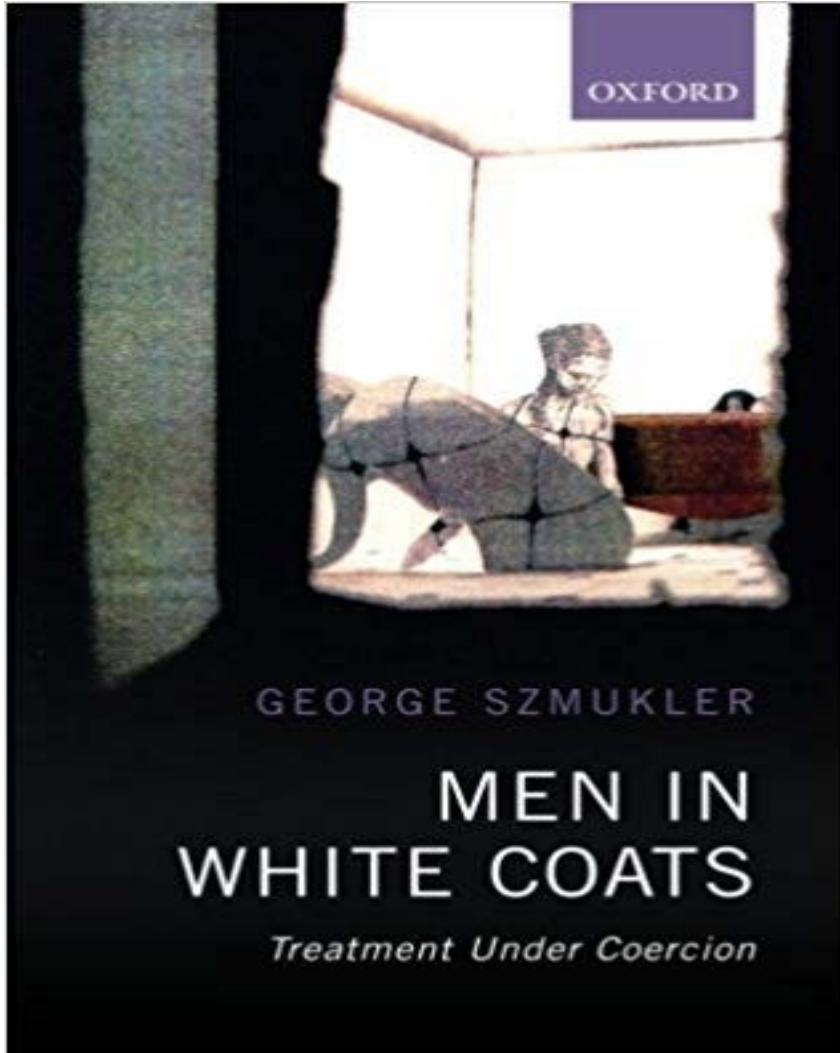
- What level of documentation is required in instances of unwise decisions?
- How many people need to 'sign off' the unwise decision?
- What is considered reasonable to have undertaken in outlining risks?
- What protections will be in place for staff where an unwise decision results in an adverse outcome?

# Tackling a risk adverse culture

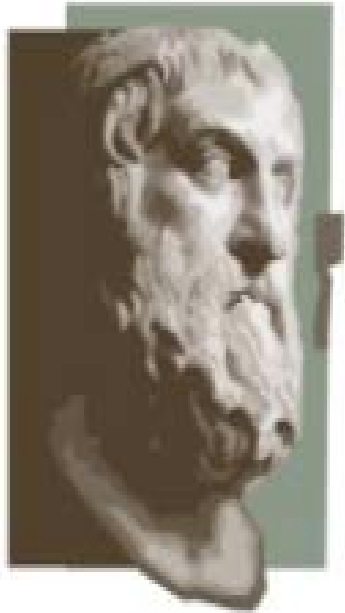




# New approach to risk?



‘The sad truth is that we are very poor at predicting the very events that are the most tragic and that we most wish to prevent’  
(2017:40)



*“First do no harm.”*

Hippocratic Oath

# Primary legislation and other codes



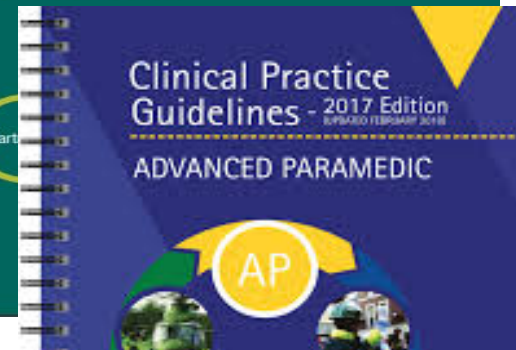
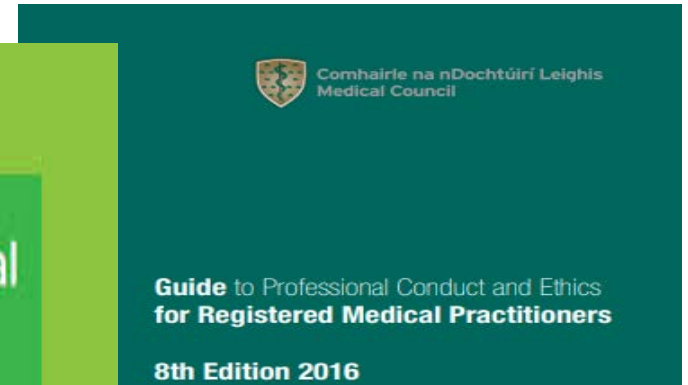
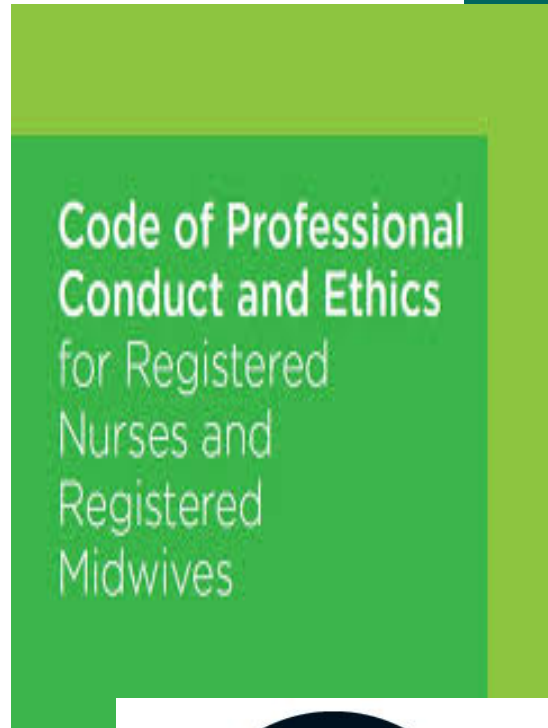
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*Number 64 of 2015*

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**Assisted Decision-Making (Capacity) Act 2015**

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**Ag Rialáil Gairmithe Sláinte  
agus Cúraim Shóisialaigh**

**Regulating Health +  
Social Care Professionals**

# Existing capacity assessment tools




## Mini-Mental State Examination (MMSE)

Patient's Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Instructions:** Ask the questions in the order listed. Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day of the week? Month?"
5		"Where are we now: State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible. Number of trials: _____
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Stop after five answers. Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

(Adapted from Rovner & Folstein, 1987)





# Next of Kin



**"If you order the chili, I need  
to know your next of kin."**

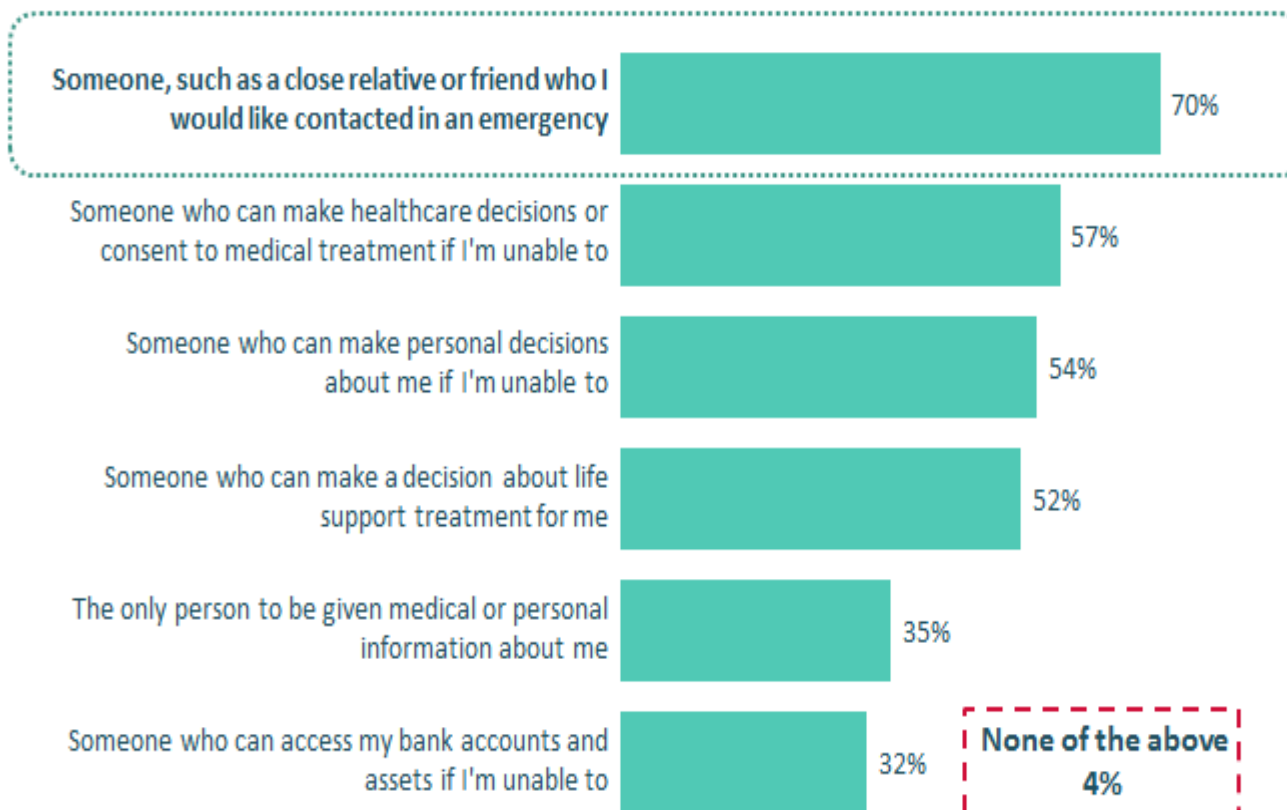
# Next of Kin

No Legal Authority to consent or refuse treatment on behalf of another



# Which of the following do you feel is the role of your 'Next of Kin'?

(Base: All Adults; n=1,020)



7 in 10 believe that 'Next of Kin' is somebody to be contacted in an emergency. More than half believe 'Next of Kin' is associated with making healthcare or personal decisions on their behalf, if they are unable to do some themselves. Only 4% do not associate the role of 'Next of Kin' with any of the statements.

REDC

(Q.1)

# Decision Support Service



Decision  
Support  
Service

# Director- Aine Flynn



# DSS Activity 2019

- Staff now being recruited
- 17 codes of practice
- National Consultation on all of the codes
- Public Information Campaign
- Establishment of panels and registers



**About US :**

A blue pencil is shown from a high angle, drawing a thick blue line that underlines the text 'About US :'. The pencil is positioned at the end of the line, with its tip touching the line. The background is a plain, light gray surface.



# Role of the HSE National Assisted Decision-Making & Consent Office

- Support for front line services
- Guidance and documentation
- Education and training
- Draft Codes of Practice
- Website and information



what  
are we *doing?*

# Work of the office 2019

- On-going briefing sessions on the Act
- Education and training programme- E-learning
- Draft Codes of Practice- ADM, AHD
- Review of the National Consent Policy
- Review of DNA-CPR Policy
- Masterclass series- Autumn 2019 on Consent, Supported Decision-Making and the functional assessment
- Collaborative working- CHO's, HG's, DSS

ONE BITE at  
a TIME



SEAN  
SALLO 2011

# More information

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# Helpful links

Framework for Improving quality

[www.qualityimprovement.ie](http://www.qualityimprovement.ie)



Improvement Knowledge  
and Skills Guide



<http://www.hse.ie/eng/about/Who/QID/aboutQID/>

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QITalktime page**

**Only x3 more webinars left before the summer break 😊**

**Next Webinar: Tues 28th May 1-2pm:**

**A more organised approach to Quality Improvement  
The NRH**

**Thank you from all the team @QITalktime**

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Improvers**