



# Ireland's Assisted Decision Making Capacity Act—the potential for unintended effects in critical emergencies: a cross-sectional study of Advanced Paramedic decision making

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## Abstract

**Objective** Irish legislation on Advance Healthcare Directives (Assisted Decision Making Capacity Act 2015, ADMC) proposes to change the basis of decision making from acting in the patient's best interests to following the expressed will and intentions of the patient. Refusal of life-saving care can occur, without sound reasons. The implications for care in life-threatening emergencies have not been explored among clinicians.

**Design** An anonymous questionnaire survey of Advanced Paramedics (AP) covering awareness of the legislation, attitudes to and experience of refusal of care and potential actions in emergency scenarios now and if the legislation were in force. The scenarios covered end-of-life and deliberate self-harm situations potentially requiring resuscitation.

**Setting** All 482 graduates of the Advanced Paramedic Training Programme were invited to take part.

**Results** Overall, 85/389 (21.9%) valid contacts responded, with demographic characteristics similar to the overall population. Attitudes ranged from highly positive to highly negative in relation to the potential impact of the legislation on professional and operational responsibilities. Respondents described marked changes in whether they would offer resuscitation if the ADMC were in place.

**Conclusion** Irish legislation which changes the traditional basis of medical practice away from the best interests of the patient may affect the resuscitation practices of Advanced Paramedics in life-threatening situations. It has significant implications for medical education, professional practice and clinician-patient interactions. This legislation and similar planned legislation may have implications for other EU jurisdictions.

**Keywords** Ethics · Health policy · Medical law · Resuscitation

## Article summary—strengths and limitations of the study

- Ireland is changing its laws to require the patient's 'will and preferences' to dictate care instead of the clinician's perceptions of the patient's 'best interests'.
- Refusal of care can occur, even if this leads to death.
- First research to explore the impact of these changes—survey with low response rate but key provider group.
- Advanced Paramedics report significant potential changes in resuscitation practice, in key scenarios.
- There may be implications for practice elsewhere in the EU.

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## Introduction

Four broad principles have guided clinicians in making ethical decisions while caring for their patients: beneficence, non-maleficence, respect for autonomy and justice [1, 2]. In professional and clinical terms, a clinician who acts in the best interests of a patient is perceived as meeting those requirements [3, 4]. New legislation to be implemented in Ireland introduces a different framework for medical decision making and raises potential conflicts between the legal and ethical obligations of clinicians in emergencies.

The Assisted Decision Making (Capacity) Act 2015 was passed by the Oireachtas (Irish Houses of Parliament) in 2015; some but not all of its provisions have been implemented since then [5]. The purpose of this legislation is to ensure that persons who may require assistance with exercising their decision-making capacity, whether immediately or in the future, have the necessary legal and healthcare structures in

place to do so. It provides for a clear definition and tests for capacity and provides a legislative basis for Advance Healthcare Directives (AHDs) and a Director of Decision Support Services within the health service.

In an explanatory note published by the Oireachtas Library and Research Service in May 2017, the ADMC is described as applying principally to people with intellectual disability, degenerative cognitive conditions and mental health illnesses but is not limited to those groups. The Act is aimed at making a cultural shift from the ‘paternalistic approach’ of the Wards of Court system to a rights-based one, in which the person’s ‘will and preferences’ must be taken into account [6]. AHDs are intended ‘to come into effect if the author subsequently loses decision-making capacity’ [2].

An AHD can be used to refuse treatments, including life-saving ones; it must specify the treatments (and the circumstances of their use) which are being refused and must clearly state that the person understands that this may lead to their death. At a minimum, an AHD must be in writing, must specify the treatments which are refused and the relevant circumstances and must be signed by the person involved and two witnesses (one of whom is not an immediate relative). There is no requirement for legal or other professional involvement.

Section 83 of the Act (Appendix 1) has yet to be implemented. It specifies that the ‘will and preferences’ of a person aged 18 or over who has capacity should determine their treatment. It sets out broad grounds for refusal of treatment by a person with capacity including refusal in circumstances where the decision:

- i. is unwise or
- ii. is not based on sound medical principles or
- iii. may lead to the person’s death.

The presumed intention of Section 83 is to support those patients who refuse onerous or distressing treatments in the course of a chronic or terminal illness. However, it will also, if implemented, apply to a range of emergency situations in which Emergency Medical Services personnel or general practitioners make on-the-spot decisions about initiation of treatment. Such situations include calls to unresponsive patients who have taken overdoses or have inflicted other forms of serious self-harm, including hanging. Current practice is to provide all life-saving treatments to patients in these situations, on the understanding that implicit consent is provided and that the practitioner is acting in the patient’s best interests. Both the Medical Council of Ireland (Appendix 2) and the Pre-Hospital Emergency Care Council (PHECC) (Appendix 3) require registered practitioners to act in this fashion [7, 8]. It is unclear how Section 83 will affect current practice if implemented. If a GP or EMS staff arrives to an unresponsive patient who appears to have a valid AHD refusing treatment, how should they act? Limited information currently exists

on the characteristics and outcomes of patients who refuse emergency care [9, 10, 11].

In Britain, the Mental Capacity Act 2005 covers advance directives and sets out grounds for assessment of capacity. It specifies that ‘An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests’. The General Medical Council requires doctors to provide life-saving treatment (Appendix 4) but notes that consideration should be given to views previously expressed by the patient. Paramedics registered with the UK Healthcare Professions Council are required to obtain informed consent before giving treatment, except in an emergency [12]. In most jurisdictions, doctors and paramedics receive similar guidance from their professional bodies: act immediately in the patient’s best interests by providing essential, life-saving treatment but obtain informed consent for any further action.

Ireland’s ambulance services are professionally regulated by PHECC, a statutory agency which maintains all registers and is responsible for training and professional standards. The National Ambulance Service (NAS) and Dublin Fire Brigade (DFB) share responsibility for provision of emergency ambulance services. All emergency ambulances are staffed by Paramedics and/or Advanced Paramedics (APs). APs provide advanced life support, represent the highest level of clinical decision making within the ambulance services and may withhold or cease resuscitation in circumstances currently defined by their Clinical Practice Guidelines [13]. The National Suicide Research Foundation reports 399 suicides in Ireland in 2016 [14]. The National Self-Harm Registry reports 11,600 episodes of self-harm by 9103 people in 2017 (a 21% increase on the 2007 figure), two-thirds of which involve overdoses of drugs [15]. No ambulance service data are available on their involvement with these incidents but a high level of engagement is likely.

The purpose of this study is to explore the knowledge, understanding and views of Advanced Paramedics of the implications and possible effects of Section 83, if implemented. Further research is planned with other clinician groups who may be affected by the legislation.

## Methods

UCD Centre for Emergency Medical Science is the sole approved agency for Advanced Paramedic training in Ireland and has graduated 482 students since the role was established in 2005. Students are Paramedic members of staff nominated by NAS or DFB, with a small number drawn from Ireland’s Defence Forces. The study comprised an anonymised, on-line questionnaire sent to all graduates of the AP training programme. The ADMC was briefly introduced and the survey

included a copy of Section 83 which respondents were asked to consider when answering parts 2 and 3.

Part 1 of the questionnaire included questions on demographics, experience in AP practise, awareness of the ADMC and views on its potential impact.

Part 2 asked respondents to offer examples (free text) of situations in which a patient with capacity might validly refuse treatment in an emergency if:

- i. The decision is unwise
- ii. The decision is not based on sound medical principles
- iii. The decision may lead to the person’s death.

Part 3 presented two case scenarios in which patients are in imminent danger of death (one self-harm, the other palliative care) and asked respondents to consider how they might respond now and after the potential implementation of Section 83.

Chi-square goodness of fit tests were used to compare key characteristics of respondents and all graduates. Research ethics approval was provided by UCD Human Research Ethics Committee (October 2017) and the study received no funding support from any external agency.

Patient and public involvement: no patients or members of the public were involved in the study, which was limited to graduates of the Advanced Paramedic training programme.

## Results

All graduates of the AP training programme were emailed an invitation to take part and a survey link. Of 482 electronic invitations, 93 were identified as inactive or wrong addresses or individuals had died or retired, leaving 389 possible respondents. In all, 85/389 (21.9%) responded. Table 1 summarises their key characteristics and indicates that there was no statistically significant difference between respondents and the overall population of APs in gender, age or duration of service. The limited response rate and relatively high level of awareness of the ADMC among respondents (65.9%) may indicate that this group is not representative of the population of APs. However, we believe the data collected provides significant insight into issues of importance to all EMS practitioners and will offer a framework for further research and reflection.

Table 2 indicates the diverse views among respondents about the impact of Section 83. High proportions indicate that their work may be easier (50%) or more difficult (33.3%) as a result. Disagreement also exists about the possible positive (43.5%) or negative (38.8%) impact of the Section on the professional Code of Conduct which must be adhered to by all registrants.

**Table 1** Characteristics of respondents and all graduates

	<i>n</i> = 85 respondents	<i>n</i> = 482 all graduates	<i>p</i> value*
Age groups			0.116
25–39	30 (35.3%)	130 (27.0%)	
40–55	51 (60.0%)	308 (63.9%)	
> 55	4 (4.7%)	44 (9.1%)	
Gender (male)	74 (87.1%)	414 (86.0%)	0.811
Years in AP practice			0.056
Up to 5 years	54 (63.5%)	242 (50.2%)	
6–10 years	25 (29.5%)	192 (39.8%)	
> 10 years	6 (7.0%)	48 (10.0%)	
Currently in AP practice? Yes	83 (97.6%)	–	
Confident in assessing capacity? Yes	77 (90.6%)	–	

\*Chi-square goodness of fit test

Tables 3, 4 and 5 categorise the free text examples which respondents offered, of the ‘unwise’, ‘not based on sound medical principles’ and ‘might lead to death’ grounds on which a patient might refuse care. Many of the examples came up in each of the three categories. It is noteworthy that in many cases, respondents cited personal experience of such situations, rather than offering theoretical possibilities. These grounds were pragmatically grouped into four broad categories—clinical, attitudinal, chronic disease and comprehension issues. Where the issues (particularly in the clinical category) were cited in each of the three areas, they are not repeated in each table.

**Table 2** Attitudes to ADMC

	<i>n</i> = 85
Aware of ADMC 2015	
Yes	56 (65.9%)
No	24 (28.2%)
Other	5 (5.9%)
Section 83 will:	
make my job easier	42 (50.0%)
make my job more difficult	28 (33.3%)
will have no effect on my job	14 (16.7%)
Have you received guidance on ADMC from your employer?	
Yes	13 (15.3%)
No	67 (78.8%)
Other	5 (5.9%)
In relation to the PHECC Code of Conduct, the ADMC will:	
complement the Code	37 (43.5%)
undermine the Code	33 (38.8%)
have no effect	15 (17.6%)

**Table 3** Examples of reasons for refusal of care which are ‘unwise’

Clinical	Attitudes	Chronic illness	Comprehension
Unexplained LOC	‘Choose to die’	Palliative care	Intellectual disability
Injuries requiring ED care	Avoidance of ED/delays	Complex co-morbidities	Consequences not understood
Overdose	Avoidance of issue		Benefit of care not understood
Serious depression	Family/peer pressures		
Unexplained symptoms	Religious reasons		
ECG abnormalities	Domestic issues		
Head injuries			
Anti-coagulated, injury			
Continuing chest pain			
Sepsis			

Clinical issues such as ECG changes, chest pain, wounds or a collapse followed by apparent recovery are examples of situations where a clinician may be concerned for the patient, but individual patients may disagree and refuse care.

Attitudinal examples included avoidance of the Emergency Department, concern about waiting times, fear of hospital, previous bad experience or media reports. Respondents repeatedly cited pressure from family or peers or domestic pressures as reasons for refusal of care.

Chronic illness was cited in terms of distress caused by repeated Emergency Department visits and discharges, inability of services to deal with the complexity of patients with multiple problems or a wish to die at home, regardless of the availability of palliative care.

In terms of comprehension, it was striking that many respondents cited the Internet as a source of misleading information for patients and emphasised the difficulties they had experienced as a result of refusal of care based on inaccurate or inappropriate information. This was particularly notable among reasons for episodes of refusal of care which were ‘not based on sound medical principles’.

Appendix 5 outlines the case scenarios which respondents were asked to consider. Table 6 outlines their choices in terms

of offering or withholding resuscitation. It is notable that significant change would happen in both scenarios, if Section 83 were implemented. In the self-harm scenario, after implementation of Section 83, 20% fewer respondents offered resuscitation and more than 20% did not know how they would act or required other information. In the end-of-life scenario, around a fifth of respondents are unsure how they would act both currently and in the future; however, after implementation of Section 83, an additional 12% would withhold resuscitation.

Most respondents added free-text comments, reflecting on the challenges they may face in implementing the ADMC. They stress the need for clear policy guidance and education from their employers and professional bodies as well as support in dealing with the complex situations that may arise. Many respondents expressed concern about their personal exposure in these situations and the potential stresses associated with making such decisions.

## Discussion

A clinician who acts in the best interests of his or her patient has traditionally been viewed as acting appropriately. The

**Table 4** Additional examples of reasons for refusal of care which are ‘not based on sound medical principles’

Clinical	Attitudes	Chronic illness	Comprehension
Dehydration	Belief in self-coping	Carer for another	Misinformed by the Internet
Now well after significant event	Fear of hospital		Misinformed by peers/family
	Bad previous experience in ED		
	Denial of illness		
	‘I am a doctor’		
	May not be allowed home again		
	Herbal/astrology cures best		
	Relative died in that hospital		

**Table 5** Additional examples of reasons for refusal of care ‘which may lead to his or her death’

Clinical	Attitudes	Chronic illness	Comprehension
–	Carer concerned, patient not	‘Exhausted by multiple ED attendances’	–
–	Withdrawal from treatment	Want to die at home, in terminal illness	–

ADMC introduces a new legal framework for appropriate actions, based on compliance with the expressed will and preferences of the patient. It implies that an approach to patient care based on ‘best interests’ is paternalistic, in that another person (the clinician) is attempting to make judgements on behalf of the patient. In many cases it is likely that the patient’s ‘expressed will and preferences’ will match the healthcare professional’s perception of their ‘best interests’; however, the data collected in this study suggest that in emergency situations, the potential exists for conflict between the two.

A large majority of respondents proposed to resuscitate the self-harm patient in scenario 1, although she had expressed a wish to die at a time when she had capacity. If Section 83 were in place, fewer respondents proposed to resuscitate this patient; however, a much larger group was uncertain about how they would act. Although a hypothetical situation, this outcome would appear to place APs in conflict with the ADCM, if fully implemented. In the end-of-life scenario, most respondents would withhold resuscitation; this proportion increased with implementation of Section 83 but many respondents were unclear about how they would act. The reported uncertainty about how to act and the changes in practice would appear to result from the respondents’ interpretation of the requirements of Section 83. The implications for medical education, for professional aspects of practice and potentially for medicolegal practice remain to be explored.

The ADCM specifically details a likelihood of death as an acceptable basis for refusal of treatment by a patient with capacity. Although suicide is no longer an offence in Ireland, no legislative framework exists for ‘assisted dying’; concerns were expressed by some respondents that the ADCM effectively formalises suicide through a decision to refuse care. If that decision is the ‘expressed will and preference’ of the patient but the judgement of the attending clinician differs (that resuscitation is in the patient’s best interests), then a conflict exists. Few doctors, nurses or paramedics have prepared themselves to stand back while a patient, who could be resuscitated, dies; many will feel that they

cannot in good conscience do so. The ADCM makes no provision for conscientious objection by healthcare professionals; the Code of Practice (England and Wales) for the UK’s 2005 Mental Capacity Act makes some provisions for conscientious objection by healthcare professionals [16]. This issue should be considered in amendments to the Irish legislation. Furthermore, Section 26 (5) of the UK legislation specifically allows for the provision of ‘life-sustaining treatment’ while the assistance of the courts is sought.

BMA guidance explores the UK legislation in depth and offers useful guidance on its interpretation [17]. However, that guidance emphasises the importance of the patient’s ‘best interests’ and urges ‘reasonable’ actions by doctors—the Irish legislation’s focus on the patient’s ‘expressed will and preference’ is quite different to that of its UK counterpart.

It is also noteworthy that further legislation in relation to the reform of mental health services in Ireland has been through a number of stages before the Oireachtas. The campaign group supporting the Mental Health (Amendment) Bill 2017 describes its purpose as:

Replace the existing principle of ‘best interests’ under the Mental Health Act, 2001. This principle has been interpreted very paternalistically in the Courts and has sustained a culture where, at times, the views of the doctor have been given priority over the views of the service user. The Bill would replace ‘best interests’ with the guiding principles of the Assisted Decision-Making (Capacity) Act 2015 (for example, respecting the will and preferences of the person). It empowers people to be the decision-makers over their own care [18, 19].

The implications of Section 83 may go beyond those of challenges to practitioners in Ireland. While the EU has no overarching legislation defining codes of medical conduct, the Conseil Européen de Ordres de Médecin (CEOM) is a

**Table 6** Responses to case scenarios

	Resuscitate	No resuscitation	Do not know	Other
Scenario 1				
Currently	80 (94.1%)	1 (1.2%)	1 (1.2%)	3 (3.6%)
If S83 activated	63 (74.1%)	2 (2.4%)	9 (10.6%)	11 (12.9%)
Scenario 2				
Currently	10 (11.8%)	54 (63.5%)	4 (4.7%)	17 (20%)
If S83 activated	3 (3.6%)	64 (76.2%)	3 (3.6%)	14 (16.5%)

long-standing forum of all EU medical regulators, with an advisory role to the EU Commission. Its 2011 ‘European Charter of Medical Ethics’ says the physician must act in the patient’s interest and ‘is not required to satisfy requests for treatment which he does not approve’ [20]. Such charters and codes are, of course, non-binding in Irish law but implementation of the ADMC may generate significant debate internationally.

In this study, respondents provide considerable data on the many potential issues to be considered under the three categories in which refusals may occur in the ADMC. Of note is the variety and complexity of reasons for refusing care for clinical issues that could benefit from ED assessment or treatment; they include issues of complex chronic disease, a patient’s genuine wish to die and the influence of outside agents. Of note is the widespread experience by APs of patients who rely on the Internet to help them make decisions about their care but often using unreliable sources. The need for clarification of roles and procedures is clear, as is the need for guidance from professional and employment bodies. The wide range of interpretations of the possible impact of this legislation by respondents—with significant proportions each believing that the ADMC will help, hinder or have no effect on their roles—suggests the need for mechanisms to ensure consistency of approach.

The ADMC 2015 raises important ethical, moral, legal and practical problems for healthcare professionals dealing with critical emergencies, especially in the pre-hospital environment where available time and professional supports are at a premium. Furthermore, it mandates a fundamental change in the basis of medical practice in Ireland from the long-standing principle of acting in the patient’s best interests to following the patient’s expressed will and intentions. That change seems likely to be further embedded in additional legislation now proceeding through the Irish parliamentary system. Such a fundamental change in the principles underpinning medical practice has broad implications; this study suggests the potential for unintended effects on life-saving care.

**Contributorship statement** GB developed the study, GB and ME developed the study instruments and HT and AT disseminated survey and analysed results. All are responsible for the drafting of the paper.

### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

All study participants provided informed consent.

**Data sharing** No additional data available.

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