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# Do not attempt cardiopulmonary resuscitation practice and policy in Ireland: a mixed-methods study of service user and advocacy group perspectives

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## Abstract

**Background** Cardiopulmonary resuscitation offers the potential to save a person's life. However, this highly invasive medical treatment is not always appropriate, and the likelihood of success is relatively low. In Ireland, the Health Service Executive (HSE) National Consent Policy establishes the national guidance in respect of DNACPR decisions, and this was supplemented by HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic. Previous research on DNACPR practice in Ireland concentrated on the perspective of the medical and nursing professions and was completed prior to publication of the supplementary guidance. In contrast, this article reports on research which investigates service user and advocacy group perspectives on DNACPR practice and policy in Ireland.

**Methods** The research utilized mixed methods design to collect quantitative and qualitative data. A questionnaire with close-ended and open-ended questions was distributed via Qualtrics, targeting the public while explicitly excluding healthcare workers to focus on patient and caregiver experiences. Recruitment involved identifying relevant advocacy and state organizations and leveraging professional networks and social media to maximize participation and minimize selection bias. Recruitment was conducted through collaboration with organizations that advocate for individuals affected by DNACPR decisions. Survey data were analysed in SPSS for closed questions and thematic analysis for open responses. Four semi-structured interviews with representatives of advocacy groups were completed, transcribed and analysed using thematic analysis. The qualitative and quantitative data's reporting rigour was guided by the CROSS and SRQR guidelines.

**Results** A total of 148 participants completed the survey, and 4 interviews were completed with representatives of advocacy groups; 70.5% ($n = 98$) selected the correct definition of a DNACPR decision. Many survey participants overestimated the rate of survival for both in-hospital and out-of-hospital cardiac arrest. There was a strong desire for involvement and support in the decision-making process. Interviewees drew attention to poor awareness of national policy, uncertainty as to the decision-making authority of family members and difficulties in communication. Interviewees also highlighted the need for additional information concerning the nature of DNACPR and CPR.

**Conclusions** The research study highlights points of weakness in the DNACPR decision-making framework for service users. While there is a desire to be involved in the DNACPR decision-making process, this is challenged

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by deficiencies in the understanding of CPR and uncertainty surrounding decisional authority. The decision-making framework may be strengthened by the development of accessible information and educational resources.

**Keywords** Advance care planning, Autonomy, Decision-making, Do not attempt cardiopulmonary resuscitation, End-of-life

## Background

Cardiac arrest is a serious medical emergency, and in the right context, cardiopulmonary resuscitation (CPR) can save a person's life. However, it is a highly invasive medical treatment, not always appropriate, and the likelihood of success is relatively low [1, 2]. Many in the general population overestimate its effectiveness and underestimate the physical trauma involved in a resuscitation attempt. The coronavirus disease 2019 (COVID-19) pandemic shone a spotlight on Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision-making policy and practice, from which concerns emerged about inadequate consultation and communication in respect of decision-making for DNACPR, particularly in residential care settings [3]. DNACPR decisions primarily address whether CPR should be attempted in the event of cardiac or respiratory arrest rather than the full spectrum of advanced life support measures.

The legal framework in Ireland for DNACPR decision-making is quite broad, as it framed by human rights as recognized by the Irish Constitution and the European Convention on Human Rights, legislation, case law, professional standards and policy. It is a hierarchical system in which certain sources will prevail over others where a conflict arises. National guidance in respect of DNACPR decisions is established by the Health Service Executive (HSE) National Consent Policy [4]. This guidance has been supplemented by the HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic, published in May 2020 [5]. It was intended that the supplementary guidance be read in conjunction with the HSE National Consent Policy along with several pandemic-related policies. The supplementary guidance is now included as Appendix One in the HSE National Consent Policy.

The HSE National Consent Policy and the supplementary guidance are underpinned by respect for human rights and align with the broader legal framework. These documents apply in all locations where care and treatment are provided by or on behalf of the HSE. Individual healthcare facilities have local policies and guidance which influence and inform the care and treatment provided. Although these local and regional policies should derive from the National Consent Policy, there appears to be a degree of inconsistency in how such decisions are made and recorded as well as a "lack of clarity about the roles and responsibilities" of everyone involved in the decision [4]. DNACPR decisions should be based on an individual assessment of each person and clinical judgement. Discussions regarding advance DNACPR decisions should involve the person and be made in the context of the person's overall goals and preferences for treatment and care considering the likelihood of success and potential risks and harms [4].

A DNACPR decision may also be provided for within an advance healthcare directive. Part 8 of the Assisted Decision-Making (Capacity) Act 2015 establishes a statutory basis for advance healthcare directives in Ireland. The relevant provisions commenced in April 2023, prior to which the legal status of advance healthcare directives was defined by case law in the jurisdiction.

A recent literature review highlights issues with the level of patient or family involvement in the decision-making process and the communication of a decision, as well as conflicts in relation to the actual making of a DNACPR decision [6]. The review examined barriers and facilitators in DNACPR decision-making, processes and implementation, analysing articles published between 1 January 2013 and 6 April 2023. It formed part of a larger project of which the research in this article is one part. The project included a review of terminology, international law and policy, as well as perspectives from healthcare workers, representative bodies, service users, families and advocacy groups on DNACPR decision-making. For the purpose of this research, "service user" is understood in broad terms to include patients, family members and other individuals engaging with the health service.

In the Irish context, complaints and reported incidents point to considerable confusion about the DNACPR decision-making process and about the roles and responsibilities of the parties involved, in particular close family members [7, 8]. Previous research on DNACPR practice in Ireland largely concentrated on the perspective of the medical and nursing professions [9–11]. This study examines service user and advocacy group perspectives on DNACPR policy and practice in Ireland to inform a new policy framework. Informed by the recent literature review [6], key areas for further investigation include knowledge of DNACPR policy and practice, discussion and involvement in DNACPR decision-making, communication of a DNACPR decision and conflicts arising in the DNACPR decision-making process.

## Research methodology

This study utilized a mixed methods design (survey and semi-structured interviews). Quantitative and qualitative data were collected to best understand the challenges related to DNACPR practice and policy in Ireland. The study adhered to the Consensus-Based Checklist for Reporting of Survey Studies guidelines (Supplementary File S1) [12] and Standards for Reporting Qualitative Research guidelines (Supplementary File S2) [13].

### Survey

A questionnaire was developed for this study on the basis of a review of the literature, a review of complaints and incidents related to DNACPR practice, a review of international practice and policy and stakeholder engagement. The HSE DNACPR Research Project Working Group, consisting of legal and healthcare professionals as well as patient representatives, provided comments and feedback at each stage of questionnaire development. Once all questions were agreed upon, the questionnaire was uploaded to the online survey platform, Qualtrics. The survey underwent pre-testing with three healthcare workers, three members of the public and four quantitative research experts. The process focussed on assessing face validity, content validity, clarity and suitability of the questions. On the basis of the written and oral feedback received, minor revisions were made before finalizing the survey for distribution.

The questionnaire was composed of 26 questions across five subsections, specifically: demographic and personal characteristics (questions 1–5), knowledge of DNACPR and policy (questions 6–13), involvement in DNACPR decision-making (questions 14–18), DNACPR discussion (19–21) and communication of and adherence to the DNACPR decision (questions 22–25). An additional open-ended question, number 26, provided participants with an opportunity to include further comments on the topic of DNACPR practice and policy.

An information letter along with the hyperlink for the online questionnaire was provided to relevant state and advocacy groups for circulation amongst their members (Supplementary File S5). Relevant bodies were identified by the researchers in conjunction with a Health Service Executive senior project manager. Survey details were shared with groups such as the Disability Support Service, SAGE Advocacy, Irish Hospice Foundation, National Advocacy Service for People with Disabilities, National Federation of Voluntary Bodies, Third Age Ireland, Age Action Ireland, Safeguarding Ireland, Irish Cancer Society, Alzheimer Society of Ireland, Neurological Alliance of Ireland, Patients for Patient Safety Ireland, Family Carers Ireland, Inclusion Ireland, Care Champions Ireland, Irish Patients Association and Cairde. The survey was shared through members of the HSE DNACPR Research Project Working Group. In addition, information about the questionnaire was shared through personal and professional social media channels. This approach ensured an opportunity for people nationally to engage with the study and to contribute their perspectives, thereby reducing selection bias. Responses to the questionnaire were anonymous. The questionnaire landing page explained that healthcare workers were not to complete this questionnaire, as a separate questionnaire would shortly be made available for them.

The questionnaire was open for responses from 28 August 2023 until 25 September 2023 and 148 participants completed the questionnaire. Survey data were analysed in SPSS and qualitative data from the open-ended question were analysed utilizing thematic analysis [14]. Missing data were excluded from statistical analysis.

### Interviews

Draft interview questions were shared with the HSE DNACPR Research Project Working Group for feedback and comment. Minor edits were implemented at this point. Interview questions were kept under review throughout the data collection stage, reflecting the iterative nature of the interview process [15]. No question was replaced or edited, although an additional probe relating to advance care planning was included [16]. The interview schedule addressed knowledge of DNACPR (questions 1–4); involvement of persons in DNACPR decisions (questions 5–8); issues arising for advocacy bodies (questions 9–11); education (questions 12–13); and a section for general comment (questions 14–16). Four semi-structured one-on-one interviews were completed with representatives of different advocacy groups in September 2023. The four advocacy groups were selected on the basis of their national roles in representing and advocating for individuals affected by resuscitation and end-of-life decision-making more broadly. These groups were the Irish Heart Foundation, National Advocacy Service for People with Disabilities, SAGE Advocacy and Irish Hospice Foundation. Interviews included a mix of face-to-face and MS-Teams-based interviews. Each interview was audio recorded and was subsequently transcribed by a professional transcription service and analysed using a thematic analysis framework [14].

### Ethical considerations

Full ethical approval for this study was obtained from the University of Limerick Faculty of Arts, Humanities and Social Sciences Research Ethics Committee (reference 2023-04-23-AHSS). Participants were recruited after receiving all relevant information, which included a full explanation of the study's purpose and procedure. Participants were aware of the study's risks and benefits and could withdraw from the study, or the survey could be stopped at any time. Informed consent was recorded for all participants.

**Table 1** Participant demographics

| | | |
|---|---|---|
| Gender | Man | 19.59%, *n* = 29 |
| | Woman | 79.05%, *n* = 117 |
| | Non-binary | 0.68%, *n* = 1 |
| | I identify my gender as: male | 0.68%, *n* = 1 |
| Age | 18–29 years | 2.03%, *n* = 3 |
| | 30–39 years | 10.81%, *n* = 16 |
| | 40–49 years | 23.65%, *n* = 35 |
| | 50–59 years | 35.14%, *n* = 52 |
| | 60–69 years | 18.24%, *n* = 27 |
| | 70–79 years | 9.46%, *n* = 14 |
| | 80+ years | 0.68%, *n* = 1 |
| Level of education | Secondary school | 12.84%, *n* = 19 |
| | Third level (university/college) | 87.16%, *n* = 129 |

## Results

### Quantitative data

A total of 148 participants completed the questionnaire. Participants were predominantly female, with representation for all age groups, and all had either secondary- or third-level education (Table 1). In total, 124 (83.78%) participants described their health as good or very good; only 2 (1.35%) participants described their health as poor. In addition, 33 (22.30%) participants had been involved in a DNACPR decision-making process either as a patient, family member or decision supporter within the previous 12 months.

A total of 50% (*n* = 74) of the respondents rated their knowledge of DNACPR decision-making at fair or above, and 76.35% (*n* = 113) for CPR (Table 2). Familiarity with guiding policies, legislation and decision-making instruments varied (Table 2). The HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic had the least familiarity, with only 21.91% (*n* = 32) of participants rating their knowledge of the policy as moderately familiar or above. The Assisted Decision-Making (Capacity) Act 2015 scored highest, with 54.17% (*n* = 76) rating their knowledge as moderately familiar or above.

Participants were asked to select which of the provided descriptions reflected the most accurate understanding of DNACPR. Of the 139 participants for this question, 70.5% (*n* = 98) selected "no CPR or artificial ventilation

**Table 2** Knowledge and familiarity of DNACPR, CPR and policies

**Knowledge and awareness of DNACPR and CPR**

| | Very poor | Poor | Fair | Good | Excellent |
|---|---|---|---|---|---|
| Knowledge of DNACPR decision-making (*n* = 148) | 26.35%, *n* = 39 | 23.65%, *n* = 35 | 26.35%, *n* = 39 | 20.27%, *n* = 30 | 3.38%, *n* = 5 |
| Knowledge of cardiopulmonary resuscitation (CPR) (*n* = 148) | 10.81%, *n* = 16 | 12.84%, *n* = 19 | 32.43%, *n* = 48 | 28.38%, *n* = 42 | 15.54%, *n* = 23 |

**Familiar with guiding policies**

| | Not at all familiar | Slightly familiar | Moderately familiar | Very familiar | Extremely familiar |
|---|---|---|---|---|---|
| HSE National Consent Policy 2022 (*n* = 147) | 45.58%, *n* = 67 | 12.93%, *n* = 19 | 19.05%, *n* = 28 | 13.61%, *n* = 20 | 8.84%, *n* = 13 |
| Guidance on "Do Not Attempt Resuscitation" contained in the HSE National Consent Policy 2022 (*n* = 147) | 55.10%, *n* = 81 | 20.41%, *n* = 30 | 12.93%, *n* = 19 | 6.80%, *n* = 10 | 4.76%, *n* = 7 |
| HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 pandemic (*n* = 146) | 63.70%, *n* = 93 | 14.38%, *n* = 21 | 12.33%, *n* = 18 | 6.16%, *n* = 9 | 3.42%, *n* = 5 |
| The Assisted Decision-Making (Capacity) Act 2015 (*n* = 144) | 32.64%, *n* = 47 | 13.19%, *n* = 19 | 16.67%, *n* = 24 | 27.78%, *n* = 40 | 9.72%, *n* = 14 |
| Advance Healthcare Directives (*n* = 142) | 28.87%, *n* = 41 | 17.61%, *n* = 25 | 24.65%, *n* = 35 | 21.83%, *n* = 31 | 7.04%, *n* = 10 |
| Decision support arrangements under the Assisted Decision-Making (Capacity) Act (e.g. decision-making assistant; co-decision-maker; decision-making representative; designated healthcare representative) (*n* = 141) | 36.17%, *n* = 51 | 16.31%, *n* = 23 | 17.73%, *n* = 25 | 21.99%, *n* = 31 | 7.80%, *n* = 11 |

**Table 3** Estimate of survival for in-hospital and out-of-hospital cardiac arrest

| In-hospital cardiac arrest ($n = 147$) | Out-of-hospital cardiac arrest ($n = 147$) |
|---|---|
| < 15, 14.29%; $n = 21$ | < 10, 40.14%; $n = 59$ |
| 15–34%, 33.33%; $n = 49$ | 11–29%, 28.57%; $n = 42$ |
| 35–49%, 23.13%; $n = 34$ | 30–49%, 21.09%; $n = 31$ |
| 50% +, 29.25%; $n = 43$ | 50%+, 10.20%; $n = 15$ |

**Tabel 4** Who should start the DNACPR discussion ($n = 377$)

| | | |
|---|---|---|
| The patient | 27.32% | $n = 103$ |
| Senior healthcare worker | 22.55% | $n = 85$ |
| General practitioner | 23.61% | $n = 89$ |
| Nurse | 15.12% | $n = 57$ |
| Not sure | 1.59% | $n = 6$ |
| Other | 9.81% | $n = 37$ |

Other: family ($n = 17$), consultant/physician/doctor ($n = 10$), healthcare professional ($n = 5$), friend ($n = 3$), decision supporter ($n = 1$), anyone with knowledge of health status and wishes ($n = 1$)

if a person's heart stops beating and they are not breathing", 18.71% ($n = 26$) selected "limitation of measures to preserve life which extend beyond resuscitation" and 10.79% ($n = 15$) selected "no effort should be made to preserve life". In identifying participants' best estimate as to the rate of survival to hospital discharge for a person who receives CPR for either an in-hospital or out-of-hospital cardiac arrest, 33.33% ($n = 49$) selected the 15–34% estimate of survival for a person who receives CPR during an in-hospital cardiac arrest, while < 10% was selected by 40.14% ($n = 59$) for out-of-hospital cardiac arrest (Table 3). These response options are the most accurate in each context.

As to the perceived effect a DNACPR decision would have on the quality of a patient's care ($n = 145$), 34.48% ($n = 50$) of participants felt it would have no effect, 41.38% ($n = 60$) thought it would have a positive effect and 24.14% ($n = 35$) thought it would have a negative effect. Of the 146 participants who responded to the following questions, 14.38% ($n = 21$) of participants previously had a discussion with a healthcare worker regarding what they would like to happen in the event of suffering a cardiac arrest. Additionally, 91.10% ($n = 133$) of participants want to be consulted about their DNACPR status and 82.88% ($n = 121$) would want to be offered the opportunity to have a family member, friend or decision supporter be involved in the DNACPR decision-making process. Further, 86.99% ($n = 127$) of participants felt that if their doctor did not think CPR could offer them any benefit, and did not plan to attempt CPR, they should be told, and 82.88% ($n = 121$) of participants felt that if they opted not to participate in the DNACPR decision-making process, this should be respected by healthcare workers. Regarding whom should start the DNACPR discussion, the most frequently selected response from participants was the patient at 27.32% ($n = 103$) (Table 4).

A total of 146 participants answered the question on advance healthcare directives. A total of 15.07% ($n = 22$) of participants had made an advance healthcare directive, and of these, 13 (59.09%) directives addressed cardiopulmonary resuscitation. Additionally, 147 participants responded to the next two questions, with 91.16% ($n = 134$) of participants believing that if there is a disagreement about the balance of benefits and risks of CPR, an offer of a second, independent opinion should be made to the patient. Participants varied in terms of whether a DNACPR decision should be respected if a person experienced a cardiorespiratory arrest from a readily reversible cause unconnected to their underlying illness/condition, with 36.05% ($n = 53$) agreeing, 21.09% ($n = 31$) disagreeing and 42.86% ($n = 63$) unsure. Level of comfort and timing of the discussion also varied amongst participants (Table 5).

There are many elements which may inform a DNACPR decision and Table 6 sets out participant views on the importance of policy, personal and professional influences.

The final question allowed for an open-text response so participants could add any comments on the topic of DNACPR practice and policy. A total of 44 participants provided comments which related to the subjectivity of the decision, pressure surrounding DNACPR decisions, terminology, communication, advance care policy and the need for more information to aid public awareness. The necessity of additional information concerning what is DNACPR and what CPR entails was the concern that arose most frequently in the comments.

> *Greater education and dialogue with general public on what DNACPR is, what CPR entails, and the likely success/benefits associated with it (Participant 1).*

Communication with the patient was identified and highlighted the need for meaningful engagement with the person at the centre of the decision. These comments also drew attention to the need to ensure the patient had the necessary information.

> *For patients to make an informed decision, the discussion had to be meaningful and not treated as a tick box exercise. The risks should not be skirted over but explained in detail. What the actual process of CPR is should be explained by a doctor or health professional skilled at having such conversations*

**Table 5** Level of comfort in discussing DNACPR with a healthcare worker/most appropriate time to start a discussion about DNACPR

| Most appropriate time to start a discussion about DNACPR (*n* = 416) | | Level of comfort discussing DNACPR (*n* = 145) | |
|---|---|---|---|
| While attending the GP surgery | 18.99%, *n* = 79 | Very uncomfortable | 7.59%, *n* = 11 |
| After a person is diagnosed with a terminal illness | 24.52%, *n* = 102 | Somewhat uncomfortable | 8.28%, *n* = 12 |
| During an outpatient clinic appointment | 9.38%, *n* = 39 | Neither comfortable nor uncomfortable | 15.86%, *n* = 23 |
| After a person is admitted to hospital | 17.31%, *n* = 72 | Somewhat comfortable | 26.21%, *n* = 38 |
| At the time of consent for surgery | 20.67%, *n* = 86 | Very comfortable | 42.07%, *n* = 61 |
| Not sure | 1.68%, *n* = 1 | | |
| Other, please specify | 7.45%, *n* = 31 | | |

Other: when patient is well (*n* = 6), when the person wants (*n* = 5), as early as possible (*n* = 4), diagnosis of chronic condition (*n* = 4), completing an advanced healthcare directive (*n* = 3), admitted to a nursing home (*n* = 2), any appropriate opportunity, making a will, any healthcare event, part of education, any incapacity issue, any illness, any age (*n* = 1)

**Table 6** Importance of elements informing DNACPR decision-making

| | Not at all important | Slightly important | Moderately important | Very important | Extremely important |
|---|---|---|---|---|---|
| National policy, for example, HSE National Consent Policy 2022 (*n* = 143) | 3.50%, *n* = 5 | 9.79%, *n* = 14 | 20.98%, *n* = 30 | 36.36%, *n* = 52 | 29.37%, *n* = 42 |
| Local policy (*n* = 143) | 10.49%, *n* = 15 | 11.19%, *n* = 16 | 27.97%, *n* = 40 | 32.87%, *n* = 47 | 17.48%, *n* = 25 |
| Patient wishes and preferences (*n* = 144) | 0.00%, *n* = 0 | 1.39%, *n* = 2 | 4.86%, *n* = 7 | 18.75%, *n* = 27 | 75.00%, *n* = 108 |
| Advance healthcare directive (*n* = 142) | 2.82%, *n* = 4 | 0.00%, *n* = 0 | 19.72%, *n* = 28 | 28.87%, *n* = 41 | 48.59%, *n* = 69 |
| Patient's quality of life (*n* = 143) | 2.80%, *n* = 4 | 1.40%, *n* = 2 | 5.59%, *n* = 8 | 22.38%, *n* = 32 | 67.83%, *n* = 97 |
| Input of patient's family members (*n* = 144) | 4.86%, *n* = 7 | 16.67%, *n* = 24 | 30.56%, *n* = 44 | 33.33%, *n* = 48 | 14.58%, *n* = 21 |
| Input of decision supporters under the Assisted Decision-Making (Capacity) Act (e.g. decision-making assistant; co-decision-maker; decision-making representative; designated healthcare representative) (*n* = 142) | 3.52%, *n* = 5 | 6.34%, *n* = 9 | 21.83%, *n* = 31 | 38.73%, *n* = 55 | 29.58%, *n* = 42 |
| Professional standards/code of conduct (*n* = 144) | 2.08%, *n* = 3 | 0.69%, *n* = 1 | 13.89%, *n* = 20 | 32.64%, *n* = 47 | 50.69%, *n* = 73 |
| Healthcare worker's clinical judgement (*n* = 144) | 3.47%, *n* = 5 | 4.86%, *n* = 7 | 18.75%, *n* = 27 | 48.61%, *n* = 70 | 24.31%, *n* = 35 |
| Input from other healthcare workers (*n* = 142) | 8.45%, *n* = 12 | 8.45%, *n* = 12 | 30.28%, *n* = 43 | 41.55%, *n* = 59 | 11.27%, *n* = 16 |

> *(Participant 2).*

A small number of comments drew attention to the stress and tension experienced by family members surrounding DNACPR decisions and their interpretation.

> *Sometimes families can be left with the impression that they are the ones allowing (giving permission) the DNACPR. The nuance in how the conversation is had around this is important. Some people carry the burden of "Did I make the right decision?" or conflict in the family over being blamed for something. Clarity on who makes the call for a DNACPR is important (Participant 3).*

## Qualitative data

Through thematic analysis of interview data five themes emerged, namely information and understanding of DNACPR decisions; decision-making authority; communication of a DNACPR decision; adherence to a DNACPR decision; and education and public awareness.

### Information and understanding of DNACPR decisions

The key guidance on DNACPR decision-making in Ireland is contained in Part 3 of the HSE National Consent

Policy. The policy guidance is well regarded although participants noted challenges related to awareness and accessibility of the information.

> *The consent policy in general is excellent. I think the awareness on the ground and the level to which it's put into practice; it doesn't match with the quality of the written policy.*
> *It's a dense policy, it's quite complex, there's a lot in it, so in terms of its accessibility, you know I suppose for many of the people we support who need to make decisions they're not going to go to a policy (Interview 1).*

Poor awareness of the National Consent Policy was not limited to service users but extended to healthcare workers.

> *Time and time again we come across professionals who have never heard of this policy, they don't know about the HSE's National Consent Policy (Interview 2).*

Participants highlighted challenges that service users, their families and decision supporters face in trying to understand what a DNACPR decision means for their care and treatment. This includes challenges in understanding the advice being provided by healthcare workers.

> *People don't fully understand the implications of DNACPR, or of a CPR decision, and what that might mean for a person's quality of life following resuscitation (Interview 3).*
> *In my experience that would be a misperception that people have that if they do this then people have given up all hope on them (Interview 3).*

Insufficient comprehension of the DNACPR decision-making process may also be present at an institutional level, leading to substandard practices that adversely affect the human rights of service users.

> *One of the recurring issues that we and HIQA (Health Information and Quality Authority) deal with over and over and over again is blanket DNAR policies for all people who live in certain settings (Interview 2).*
> *It seems to be misunderstood that you know everybody should have one of these on their file if they have a disability. We've come across entire services, there's one on every single file (Interview 2).*

Participants suggested that such weaknesses may be partly addressed by further emphasizing the place of human rights within the HSE National Consent Policy.

> *I would say that there needs to be a stronger link to rights, in that particular section of the document … That kind of firms up the equality of all citizens to make their own decisions and the right to refuse treatment (Interview 2).*

### Decision-making authority

Responsibility for decision-making, particularly regarding the involvement of family members, has been a source of uncertainty. There is a perception amongst parts of the public that family members have a responsibility for making the DNACPR decision.

> *Let's just say somebody ends up in a coma, their family member automatically assumes that they have a decision to make and convey to the hospital in relation to whether or not the person should be resuscitated, and it comes as an awful shock when they realize that they don't have that ability to make that decision (Interview 2).*

The confusion surrounding decision-making authority may in some cases be exacerbated by the way in which healthcare workers engage with family members or friends.

> *I had a lady who has no family; she just had one friend who visited her. And he got a call to say what will we do here. he shouldn't have been made to feel that it's actually his decision. They should've said we're just consulting you as someone who's close to her to see do you know what she might have wanted in the situation, but instead it was put to him as what will we do, you tell us (Interview 1).*

The belief that family members have some form of decision-making authority may mean that decisions are not made at an appropriate time and that important conversations do not occur. The possibility of these conversations occurring is hampered by a poor understanding of DNACPR.

> *People assume that their family would make that decision for them not knowing that they don't have the legal right to do so, also, people don't tell their family what they would want, and they can't tell their family what they want because they don't understand exactly what that means (Interview 1).*

### Communication of a DNACPR decision

Three interviewees highlighted the issue of communication, which was viewed as having a significant role in ensuring clarity and resolving tensions that might arise. A breakdown in communication could therefore result in disagreement between the various parties. One participant drew attention to the communication of a DNACPR decision to family members. There was a concern that the time should be taken to communicate a DNACPR decision to family members as this can be an upsetting experience for them.

> *A lot of the stories that I would hear would be that somebody has walked into a room to find out that a family member's been placed DNACPR, and before that's been communicated with them, so it comes as quite a shock, even if it is the right decision (Interview 3).*

Terminology arose as a specific concern in other interviews. It was suggested that the discussion should not be framed in complex terminology but should be sufficiently clear and direct that people appreciate the reality of a person's medical condition.

> *The practitioner that's delivering the message needs to be really, really clear, they have to be really direct, with what they're saying and that you know you're loved one is not going to make it. You know is going to die, the terminology that's used as well needs to be really clear (Interview 4).*

Different terminology is used to describe the decision and practice related to a person's DNACPR status. In this regard, one participant highlighted:

> *When you're talking about resuscitation, are you talking about the resuscitation of fluids, are you talking about giving antibiotics? Are you talking about you know CPR. So what resuscitation are you talking about? ... And I think that that's where we need to be clearer with the lines of resuscitation (Interview 4).*

### Adherence to a DNACPR decision

Compliance with the DNACPR decision or a presumption in favour of CPR arose across the interviews. A feeling of powerlessness can arise for healthcare workers in instances where a DNACPR decision is present.

> *I spoke with one nurse who said, if somebody has a DNACPR in their advanced healthcare directive and they have a heart attack or whatever it might be, am I just supposed to do nothing, so, there's this idea that adhering to a DNACPR is an equivalent to doing nothing for a person (Interview 3).*

### Education and public awareness

The need for education and training was noted by participants and they acknowledged the range of stakeholders for whom education and training opportunities would need to be provided. However, a hesitance amongst some persons to engage in education until it was too late was also noted.

> *It's going to be very difficult to educate people, because it's only when you're in the situation that people really pay attention to it, like they kind of look at it and they go, ah yeah, yeah, yeah nothing to do with me kind of a thing, so, it is only then when they're in a situation and that's the time that people can't actually think (Interview 4).*

Several of the interview participants considered the education of healthcare workers.

> *I definitely think targeted education of health and social care practitioners, so that the policy isn't just filed in a drawer and not known in practice (Interview 2).*
> *You could have a separate training module just on this, you could have example conversations of how to explain something. You could have example phrases to use, just that they could have to hand to review when they're having the conversation, the way to explain it in simple English, the way to check for understanding and that could have a few different examples of people, people who can only say yes or no for example it's a little more tricky to establish what they understand, and different tools that can be used, like I guess, pictures, but it would be helpful to have those widely available (Interview 1).*

These quotes illustrate the range of resources that may be required to support education and training and the variety of methods needed to ensure people can engage with the topic as widely as possible.

> *I think the key is having many, many different vehicles that will work for different people, so, videos, easy to read plain English, and I think having them in places that they're going to come across them, so like GP surgeries, community mental health, primary healthcare, hospital settings, posters, I think social media. There's a great opportunity there to run campaigns of awareness. I think stories are great vehicles that people like to hear and listen to (Interview 2).*

## Discussion

This study explored service user and advocacy perspectives on DNACPR policy and practice in Ireland. There has been a greater focus on CPR-related decisions in recent years due to factors including the COVID-19 pandemic, the availability of first responder training and the public access defibrillation programme which placed automated external defibrillators (AEDs) in many community settings in Ireland. A decision about the provision of CPR may extend beyond clinical considerations to take account of an individual's will and preferences. To determine the latter requires consultation with the individual and/or their family and friends as appropriate. This underlines the importance of capturing the perspective of service users and advocacy bodies to inform DNACPR practice and policy. In this respect, the study highlighted deficiencies in the understanding of CPR, a desire for involvement in the DNACPR decision-making process, the need for a proactive approach to DNACPR discussion, and a need for accessible information and resources to support public awareness.

Public perceptions of DNACPR are shaped by broader attitudes towards emergency and advance care planning. A report by Compassion in Dying highlighted concerns regarding DNACPR decision-making during the COVID-19 pandemic, including the lack of transparency and public misunderstanding of these decisions [17]. While the report examined the experience in the United Kingdom, this context may help explain some of the misconceptions observed in this study, particularly around the effectiveness of CPR and the role of healthcare professionals in DNACPR discussions.

Meaningful participation in a decision-making process requires an understanding of the treatment at issue and its implications for the person. While a majority (70.5% $n=98$) of survey participants identified the correct definition of DNACPR, many overestimated the effectiveness of CPR for both in-hospital and out-of-hospital cardiac arrest. For instance, 52.38% ($n=77$) of participants estimated the rate of survival for in-hospital cardiac arrest to be greater than 35%. In practice, survival to discharge for in-hospital cardiac arrest has been shown to vary from 15% to 34% [1, 18–20]. In the context of out-of-hospital cardiac arrest, 59.86% ($n=88$) of participants estimated the rate of survival to be greater than 10%. However, survival to hospital discharge after CPR in cases of out-of-hospital cardiac arrest is put at 8.8% [2]. An overestimation of the effectiveness of CPR can impact on decision-making and patient–healthcare professional relationships. Where healthcare professionals determine that CPR is not clinically indicated, a person may feel that they are being deprived of potentially beneficial treatment or that they are being abandoned by their healthcare professional at an especially vulnerable time.

The positive perception of CPR may indicate that participants do not fully appreciate the physical impact which the performance of CPR can have on a person. The provision of CPR may result in rib fractures and sternal fractures, as well as cardiac, pulmonary or intraabdominal organ injuries. An asymmetry of information may result in conflict between the service user, their family or friends and the healthcare professional. It is necessary to bridge any gap in understanding between the relevant parties. Healthcare professionals have an important role in ensuring the service user is sufficiently well informed to make a healthcare decision, although this discussion may not always occur in the context of DNACPR [21].

A desire for involvement and support in the DNACPR decision-making process emerged as a key theme in the quantitative analysis. This reflects the personal significance, which a decision on DNACPR status has for the individual. In practice, service user involvement in the decision-making process may occur less frequently [6]. Involvement may be frustrated where a service user lacks appropriate decision-making capacity [22], there may be a reluctance to raise the matter with the service user [23] or the healthcare professional's communication skills may be inadequate to ensure full involvement. In some cases, there may be concern about the physical or emotional impact which such involvement could have on the service user. McIlfatrick et al. identified emotional resistance and avoidance as barriers to engagement with advance care planning, which may further contribute to the public's reluctance to engage with DNACPR discussions in a timely manner [24], while in a survey of palliative care staff Low et al. demonstrated that most patients deal with these discussions much more positively than staff anticipate [25]. In line with this, 68.27% ($n=99$) of participants indicated that they were somewhat or very comfortable in discussing DNACPR.

Participant responses suggested that a proactive approach should be adopted in commencing a discussion of DNACPR status. Participants recognized a wide range of points as appropriate for the commencement of a DNACPR discussion, including upon diagnosis of a terminal illness, admission to hospital and attendance at GP surgery, amongst others. Discussion was not seen as being restricted to one specific point in time. Healthcare professionals need to be alert to the possibility of such a discussion. A key challenge in DNACPR discussions is ensuring engagement occurs early enough to allow meaningful participation. Underwood et al. found that individuals were more likely to want an emergency care treatment plan after developing a long-term condition (42%) or life-threatening illness (57%), suggesting that readiness to engage increases with perceived health risks [26]. This echoes the findings in the current study, as participants identified multiple points in time when DNACPR discussions should occur.

This discussion should not be thought of as an isolated event but should be part of an ongoing conversation over a longer period [27]. Such a conversation may take in a range of themes which reflects the broader complexity of resuscitation and decision-making, recognizing that DNACPR is one part of a larger clinical and ethical framework for emergency care planning. Moreover, it is necessary to distinguish these proactive discussions from emergency situations where CPR must be commenced without delay unless a DNACPR decision is recorded. Clear communication, education and documentation of DNACPR decisions in advance can reduce confusion and ensure that appropriate steps are taken in time-critical situations. The identification of multiple points for discussion provides opportunities for the service user to fully participate in the decision-making process and may allow familiar healthcare professionals to be involved in the conversation [28].

A desire for additional information regarding DNACPR was a concern that arose frequently amongst participants. This would begin to address some of the weaknesses in the decision-making process. Although it was noted in one interview that service users may not engage with these resources in sufficient time, resources for healthcare professionals were also proposed by interviewees, such as training modules on DNACPR and communication skills training. The need to enhance communication skills amongst healthcare professionals for DNACPR status discussions has previously been noted by Chen et al. [29], Einstein et al. [30], El Sayed et al. [31] and Fan and Hsieh [32].While Taubert et al. identified the use of videos, apps and websites as a way of facilitating understanding [33], the potential use and development of such resources in the Irish context requires further study.

In considering these findings, it is necessary to acknowledge the strengths and limitations of the study. The combination of quantitative and qualitative data allowed for a more comprehensive and richer understanding of DNACPR in Ireland, thereby providing insights which can inform practice and policy. The research team are not aware of any similar Irish study which captures the service user perspective on this topic. Furthermore, engagement with key stakeholders in the form of a project working group enhanced the development of the survey and interview questions and the applicability of the study's findings. Nonetheless, it is to be noted that the survey recruitment method relied on distribution through advocacy and state groups, as well as social media, which may have limited the representativeness of the sample. Participants in the quantitative component represented a highly educated cohort. A high level of education has been linked to greater healthcare literacy [34]. Moreover, 22.3% ($n=33$) of participants reported involvement in DNACPR decision-making within the previous 12 months, perhaps indicating a degree of self-selection bias. The results may therefore demonstrate a higher level of awareness and understanding of healthcare decision-making than may be witnessed in a more representative sample. As for the qualitative component, this was informed by a relatively small number of advocacy bodies and the wider applicability and relevance of some comments may therefore be questioned.

## Conclusions

The research study highlights a need to address several aspects of the DNACPR decision-making process to promote informed decision-making. At present, service users overestimate the potential benefits of CPR and do not fully appreciate the physical toll which CPR may have on the body. While there is a substantial desire for involvement in the decision-making process, there is confusion about where responsibility rests for ensuring an appropriate decision is recorded. A decision about CPR is a clinical matter which may be informed by the individual's will and preferences. This is not to suggest that the patient bears responsibility for introducing the topic for discussion or can demand treatment not in their clinical interests. Clarity around decision-making authority is a matter to be addressed more broadly within the healthcare system. An improvement in understanding of DNACPR decision-making amongst service users is unlikely to be based on a policy revision alone. Instead, the potential for information and educational resources in various forms to be made available should be explored as part of future research.

## Contribution to the literature

- This research moved beyond healthcare workers to capture the perspective of service users and advocacy groups on DNACPR practice and policy.
- This research moves beyond the National Consent Policy and includes the 'HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic'.
- Obtaining service user and advocacy group perspectives offers a clear understanding of the challenges related to DNACPR decision-making to help inform policy development and implementation.
- This research captures data on the awareness and understanding of the *Assisted Decision-Making (Capacity) Act 2015*.

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12961-025-01315-x.

Additional file 1.
Additional file 2.
Additional file 3.
Additional file 4.
Additional file 5.

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**Availability of data and materials**

No datasets were generated or analysed during the current study.

## Declarations

**Ethics approval and consent to participate**

Ethical approval for this study was obtained from the University of Limerick Faculty of Arts, Humanities and Social Sciences Research Ethics Committee (reference 2023-04-23-AHSS). Participants were fully informed about the study by an information letter and by the online survey landing page. The landing page of the online survey required consent to be given prior to commencing the survey. If a participant did not consent to take part, then the survey was automatically ended. Interviewee's informed consent was recorded by way of an ethical consent form and consent was confirmed again prior to the interview commencing.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare no competing interests.

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## Publisher's Note