

# Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis

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## Scientific summary

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# Scientific summary

## Background

Cardiac arrest is the final common step in the dying process. In the right context, resuscitation can reverse the dying process, and yet success rates are low. However, cardiopulmonary resuscitation (CPR) is a highly invasive medical treatment, which, if applied in the wrong setting, can deprive the patient of dignified death. Do-not-attempt-resuscitation (DNAR) or do-not-attempt-cardiopulmonary-resuscitation (DNACPR) decisions provide a mechanism through which decisions to withhold CPR can be taken prior to a patient sustaining a cardiac arrest.

Despite the presence of national guidelines on DNACPR decisions, recent evidence suggests wide variation in NHS organisations' policies and poor implementation of policy into practice. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report 'Time to Intervene' (NCEPOD. *Time to Intervene? A Review of Patients Who Underwent Cardiopulmonary Resuscitation as a Result of an In-Hospital Cardiopulmonary Arrest*. 2012) noted frequent failure to consider resuscitation status, a high number of futile resuscitation attempts in frail patients with substantial comorbidities, limited engagement of families and patients in reaching DNACPR decisions and 52 cases in which CPR was performed against the expressed will of the patient. Reports in the media and a 2014 judgement from the Court of Appeal further highlight difficulties in communication around DNACPR between health-care staff, patients and patients' families.

This project sought to identify the reasons why conflict and complaints arise, identify inconsistencies in implementation of national guidelines in NHS trusts, understand the experience of health professionals in relation to DNACPR, its process and ethical implications, and explore the literature for evidence to improve DNACPR policy and practice.

## Objectives

The objectives for this project were to:

- review and summarise the published evidence base informing DNACPR policy and practice
- identify the themes of current complaints/conflict in relation to DNACPR decisions and explore local solutions developed to tackle these problems
- examine current acute hospital, community and ambulance service DNACPR policies to identify inconsistencies and examples of best practice across NHS organisations
- explore health professionals' experiences of DNACPR policy and practice
- summarise, prioritise and disseminate findings from this research.

## Methods

A scoping literature review explored the evidence of interventions that improved the process or recording of DNACPR decisions. A more in-depth review explored the literature for evidence of barriers and facilitators to DNACPR decision-making (main review). For the main review, electronic databases were searched between January 2000 and July 2013. A total of 3098 unique references were identified, of which, after review, 47 were included. Study quality and risk of bias were evaluated in individual studies using the Critical Appraisal Skills Programme tool.

To determine the nature and extent of problems with DNACPR decisions in the NHS, a sample of NHS trusts were asked to provide a summary of incidents and complaints related to DNACPR decisions. In addition, the National Reporting and Learning System, the NHS Litigation Authority, the Parliamentary and Health Service Ombudsman, the Office of the Chief Coroner and Compassion in Dying's End-of-Life Rights Information Line were approached to supply information on the nature and frequency of issues related to DNACPR decision-making and implementation reported to them.

To explore consistencies and variation in implementation of national guidelines between health-care organisations, Freedom of Information requests for adult DNACPR policies were sent to a random sample of 48 English NHS trusts. DNACPR policies were assessed on their coverage of core ethical and legal issues, approaches to communication and implementation of DNACPR decisions within and between health-care settings.

Multiple, brief focus groups were used to explore service-provider perspectives on DNACPR decision-making in the NHS. Each focus group drew on one or two (of 10) pre-prepared vignettes based on cases reported in the NCEPOD 'Time to Intervene' report. Focus groups were recorded, transcribed verbatim and analysed inductively to identify major themes relating to the process of DNACPR decision-making and the ethical issues related to DNACPR. The data were initially coded, with independent coding undertaken on 25% transcripts and compared to improve the consistency of coding. Coded data were extracted thematically and discussed further by the analysis team and the themes were presented to the wider study team for further discussion, which informed the final analysis. For the ethical analysis transcripts were discussed in depth and consensus was reached on the ethical interpretation of the data. Ethical issues and values identified were considered in relation to ethical, professional and legal normative frameworks using a process of reflective equilibrium.

A joint meeting was hosted between the investigators, Dr Bee Wee (National Clinical Director for End-of-Life Care, NHS England) and Dr David Pitcher [chairperson, Resuscitation Council (UK)], with other key stakeholders, to discuss the research findings and to identify priorities for future research.

## Results

### Summary of published research evidence

A total of 84 papers were reviewed (moderate to poor quality) during the scoping review ( $n = 37$ ) and main review ( $n = 47$ ). The initial scoping review found that structured discussion following acute admission to hospital and review by specialist teams at the point of an acute deterioration improved patient involvement and decision-making. Linking DNACPR decisions to discussions about overall treatment plans gave greater clarity about goals of care, aided communication and reduced harms. Standardised documentation improved the frequency and quality of recording decisions. Patient and clinician education improved clinicians' comfort and skills about discussing resuscitation status but had mixed effects on patient involvement in discussions.

Findings from the main review were synthesised under four key domains, as follows.

### Considering the decision

Do-not-attempt-cardiopulmonary-resuscitation decisions usually involved senior physicians, nursing staff, patients and or relatives. There were discordant opinions about where the responsibility for DNACPR decisions should ultimately rest: with the senior clinician or with the patient. Three main triggers to prompt DNACPR decisions were acute admission, review by a medical emergency team or in the context of long-term care planning. Factors prompting consideration of resuscitation status were patient factors (age, comorbidities and quality of life), the likelihood that CPR would be successful and the potential for harm as a result of CPR.

### Discussing the decision

There is variation in the frequency with which the patient and his or her family members are involved. Time pressures, lack of training, discomfort with holding discussions, concerns about complaints and perceptions that discussions would cause distress were reported as barriers to discussions. Facilitators were (i) discussing treatment options as part of an overall treatment plan with a focus on treatments that would be provided and (ii) presenting options about resuscitation as routine discussions about treatment.

### Implementing the decision

Various systems exist for recording DNACPR decisions dependent on national and local policy. These range from writing in the medical/nursing notes to more formalised systems using DNACPR forms, symbols or wristbands. The rationale for a DNACPR decision was recorded inconsistently. The optimal system for recording decisions is unclear.

### Consequences of the decision

Uncertainty about the relationship between DNACPR decisions and other aspects of care led to less invasive medical treatments, reduced escalation to medical and outreach staff, fewer nursing observations, less basic care, including pain relief, and altered fluid intake. Concerns about this negative impact of DNACPR decisions sometimes impeded willingness to place a DNACPR.

### *The size of the problem*

The National Reporting and Learning System recorded 3527 incidents (0.12% of total incidents) in acute hospital settings, 844 (0.07% of total incidents) in community settings and 157 (0.98% of total incidents) among ambulance services (between January 2010 and December 2012). Overall, one-third of incidents ( $n = 1633$ ) were recorded as having caused harm, of which 106 (2.3%) noted severe harm and 148 noted deaths (3.3%). The overall frequency of incidents and complaints related to DNACPR decisions reported by trusts, relative to the total number, was small ( $< 0.5\%$ ). The most common themes were problems with communication with patients and/or relatives, disagreement with a DNACPR decision, failure to anticipate the need for a DNACPR decision, poor record keeping, poor handover of DNACPR decisions between health-care settings, failure to implement a DNACPR decision, confusion over processes for DNACPR decision-making and the need to review decisions following changes in patient status. Trusts generally responded by updating local policies and providing staff training. No evidence was submitted to demonstrate sustained improvement following these interventions.

The number of coroners' reports related to DNACPR for cases in which there was a risk of future deaths was small (0.5%). The focus of notices on NHS trusts could be broadly categorised into problems with communication (between health-care staff and the patient/relatives;  $n = 3$ ), documentation ( $n = 2$ ), staff training ( $n = 2$ ) and problems with transferring DNACPR decisions between the hospital and community settings ( $n = 1$ ). Two coroners served notices on the Secretary of State for Health suggesting a national DNACPR policy.

The Parliamentary and Health Service Ombudsman identified 33 complaints between 2008 and 2013, which were largely related to poor communication, non-consultation with family members, discussing the DNACPR with the patient against the family's wishes and ignoring verbal requests from the patient to enforce a DNACPR decision.

The Information Line received 110 telephone calls between 1 November 2013 and 30 June 2014 related to DNACPR. The main concerns of callers were being resuscitated against their wishes (53%), clinical staff being unaware of their wishes (17%) and how to request a DNACPR decision. Several callers expressed fear that there would be adverse consequences of resuscitation leading to severe impairment, while lack of information about or understanding of the process of DNACPR orders was the main reason for enquiry by others. Two callers were concerned about the fact that their relatives had a DNACPR order in place when they felt that the relative should be resuscitated instead.

### **NHS policies**

Policies from 26 acute, 12 community and 10 ambulance service trusts were reviewed. There was a lack of consistency in terminology used, which included DNAR, DNACPR, 'not for CPR' and AND (allow natural death). Only one-quarter of trusts used the standardised Resuscitation Council (UK) record form (or a modification of the form). There was variation in who could make a DNACPR decision, ranging from Foundation Year to consultant grade doctors, senior nurses or general practitioners. Most trusts recommended discussion with the patient/family and multidisciplinary team. None provided practical guidance on how to approach such discussions. Managing decisions among patients who lack capacity was less well covered. A major area of concern was the lack of portability and communication about DNACPR decisions between health-care organisations. An example of best practice was the NHS North England 'Deciding Right' policy, which provided an integrated, patient-focused approach to end-of-life care, including DNACPR.

### **Clinicians' experiences and views**

Do-not-attempt-cardiopulmonary-resuscitation decisions were considered a normal but complex part of clinical practice. Inherent uncertainties about prognosis, patient and family expectations and quality of life before and following CPR contributed to the difficulty in decision-making. Clinicians found that some patients and families thought that CPR was more likely to be successful than evidence suggests. In the case of acutely ill patients, decisions often had to be made without complete information being available. Given such uncertainty, it is perhaps not surprising that tensions between clinicians, patient and family arose and could be distressing for all involved. Because of their impact, accounts of such distress were commonly reported by clinicians, but there was no evidence that this distress was a day-to-day experience. Clinicians identified the need for skill in communication and time to seek input from family members, or where possible the patient, at the appropriate moment in the care pathway. Clinicians working in the acute setting felt that the decision should be made prior to an acute illness, while those working predominantly in a community setting were unsure when it would be appropriate to broach the issues with patients who are deteriorating gradually. The main reasons given for DNACPR decisions were a desire to avoid a futile resuscitation attempt and the harm this can cause. However, the harm described was mostly that experienced by the health professionals witnessing a futile resuscitation, with participants being less clear about harm to the patient or family. A few participants mentioned harm to society through inappropriate resource use in cases they considered futile. Many clinicians were concerned about DNACPR decisions being considered separately from the overall care of individual patients, particularly when this may lead to a reduction in the overall quality of care after a DNACPR decision is signed.

The wide range of health professionals across our focus groups shared a common feeling of ethical discomfort about DNACPR decision-making as it currently happens in practice. This arose from difficulties in interpreting specific ethical principles such as duty of care or respect for autonomy in the particular context of resuscitation decisions, and from the need to balance conflicting duties and interests in situations of uncertainty and time constraint. Participants strongly supported the principle of respecting a patient's autonomy by acknowledging the importance of discussing the risks and benefits of resuscitation with patients and informing them of any decision made. However, our data suggest that doctors avoid these conversations out of fear that the patient will ask for resuscitation and that they struggle to negotiate the limits of patient autonomy in these situations. However, they recognise that in doing so they are denying some patients their right to refuse CPR.

Our participants in general welcomed policies or guidance on DNACPR but also recognised that policies could limit professional judgement and shift the clinical focus from care of the patient to compliance with the policy. A key theme across all our focus groups was the negative impact on overall patient care of having a DNACPR decision and the conflation of 'do not resuscitate' with 'do not provide active treatment'. Overall, the strongest ethical message to come out of our data was that decisions about CPR were complex and context specific, and should be seen as one aspect of the holistic care of an individual patient.

### ***Stakeholders' priorities***

The stakeholder meeting identified five key areas (standardising NHS policies and forms, ensuring cross-boundary recognition of DNACPR decisions, integrating DNACPR decisions with overall treatment plans, tools to enhance/support clinician and patient decision-making and raising public awareness). Priorities for future research were identifying the impact of DNACPR decisions on other aspects of care and the effectiveness of different strategies to improve public education about DNACPR.

### **Conclusion**

This study found evidence of variation and suboptimal practice in relation to DNACPR across health-care settings. There were deficiencies in considering, discussing and implementing the decision, as well as widely recognised, unintended consequences of DNACPR decisions being made on other aspects of patient care.

There was support for developing standardised policies to improve consistency and ensure that decisions could transfer seamlessly between health-care settings. Integrating DNACPR decisions within overall treatment plans was seen as a key clinical priority along with developing tools to support clinicians and patients in decision-making.

### **Study registration**

This study is registered as PROSPERO CRD42012002669.

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