# FIRST LOOK SUMMARY

## HS&DR 12/5001/55

# DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) DECISIONS: EVIDENCE SYNTHESIS

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Declared competing interests of authors: GDP is a volunteer member of the Resuscitation Council (UK) Executive Committee.

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The research reported in this ‘first look’ scientific summary was funded by the HS&DR programme or one of its predecessor programmes (NIHR Service Delivery and Organisation programme, or Health Services Research programme) as project number 12/5001/55. For more information visit http://www.nets.nihr.ac.uk/projects/hsdr/12500155

The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors have tried to ensure the accuracy of the authors’ work and would like to thank the reviewers for their constructive comments however; they do not accept liability for damages or losses arising from material published in this scientific summary.

This ‘first look’ scientific summary presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not

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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, 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 cardiopulmonary resuscitation (DNAR or DNACPR) 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 National Health Service (NHS) organisation's policies and poor implementation of policy into practice. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report Time to Intervene (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 where CPR was performed against the expressed will of the patient. Reports in the media and a recent judgment 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.

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## OBJECTIVES

The objectives for this project were to:

- 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
- review and summarise the published evidence base informing DNACPR policy and practice
- summarise, prioritise and disseminate findings from this research.

## METHODS

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, NHS Litigation Authority, Parliamentary and Health Service Ombudsman, Chief Coroner's Office and Compassion in Dying, 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 health care Trusts. DNACPR policies were assessed on their coverage of core ethical and legal issues, approaches to communication and how DNACPR decisions were implemented within and between health care settings.

Multiple, brief focus groups, led by a trained facilitator were used to explore service provider perspectives on DNACPR decision-making in the NHS. Each focus group drew on one or two (of ten) pre-prepared vignettes based on cases reported in the

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NCEPOD: Time to Intervene report. Focus groups were recorded, transcribed verbatim and stored in N-vivo 10.0 (QSR International, Cheshire, UK). Transcripts were analysed inductively, using a realist approach 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, discussed further by the analysis team and the themes 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 scoping review was undertaken to explore the literature for evidence of interventions that improved the process or recording of DNACPR Decisions. Second a more in-depth review of the international literature was undertaken to explore the literature for evidence of barriers and facilitators to DNACPR decision-making. For the main review, electronic databases were searched between January 2000 and July 2013. 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 (CASP) tool.

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 (Chairman, Resuscitation Council (UK) with other key stakeholders to discuss the research findings and to identify priorities for future research.

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## RESULTS

### THE SIZE OF THE PROBLEM

The National Reporting and Learning System recorded 3,537 incidents (0.12% of total incidents) in acute hospital settings, 844 (0.07%) in community settings and 157 (0.98%) amongst ambulance services. Overall one third of incidents (n=2116) were recorded as having caused harm of which 596 (13%) noted severe harm and 141 deaths (3.1%). The overall frequency of incidents and complaints related to DNACPR decisions reported by Trusts, relative to the total number, was small (<0.5%). The commonest 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 Rule 43 Notices related to DNACPR was small (0.5%). The focus of notices on NHS Trusts could be broadly categorized 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 NHS Ombudsman identified 33 complaints 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 Helpline received 110 calls between 1st November 2013 and 30th 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. Fear of the adverse consequences

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of resuscitation leading to severe impairment were expressed by several callers, 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 that relatives had a DNACPR decision when they felt that they should be resuscitated.

### 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 Foundation Year to consultant grade doctors, senior nurses or general practitioners. Most trusts recommended discussion with the patient / family and multi-disciplinary team. None provided practical guidance on how to approach such discussions. Managing decisions amongst 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. Examples of best practice were 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

DNACPR 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 some patients and families thought CPR was more likely to be successful than evidence suggests. Decisions often had to be made without complete information being available in the acutely ill patient. Given such uncertainty it is perhaps not surprising that tensions between clinicians, patient and family arose and could be distressing for all involved. Accounts of such distress were commonly reported by clinicians because of their impact, but there was no evidence that this

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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 the decision should be made prior to an acute illness, whilst those working predominantly in a community setting were unsure when it was 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 judgment and shift the clinical focus from care of the patient to compliance with the policy. A key theme across all our

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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, context specific, and should be seen as one aspect of the holistic care of an individual patient.

## SUMMARY OF PUBLISHED RESEARCH EVIDENCE

A total of 84 papers were reviewed (moderate to poor quality). 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.

The findings from the main review were synthesized under four key domains:

### Considering the decision

DNACPR 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 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, co-morbidities, quality of life), the likelihood that CPR would be successful and the potential for harm as a result of CPR.

### Discussing the decision

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There is variation in the frequency with which the patient and 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 (ii) presenting them as routine discussions about treatment.

**Implementing the decision**

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

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### 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.

### 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 sub-optimal practice in relation to DNACPR across health care settings. There were deficiencies in considering, discussing, and implementing the decision, as well as widely recognized, unintended consequences of DNACPR decisions being made on other aspects of patient care.

There was support for the development of 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 patient in decision-making.

**Word count: 2380**

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