Managing DNACPR Recommendations in Residential Care: Towards Improved Training for Social Care and Capacity Professionals

Emily Fitton (1) 1,*, Margot Kuylen¹, Aaron Wyllie², Sabine Michalowski (1) 3, Vivek Bhatt⁴ and Wayne Martin (1) 1

Art History, University of Essex, Wivenhoe Park, Colchester CO4 3SQ, UK. E-mail: efitto@essex.ac.uk

Abstract

The use of 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) recommendations has come under scrutiny during the COVID-19 pandemic, and the Care Quality Commission (CQC) has issued a call for new standards, guidance and training. One group for whom new training is required is 'capacity professionals' working in and with residential care facilities. These professionals (including Independent Mental Capacity Advocates and Best Interests Assessors) typically have a social work background and have specialist training regarding the 2005 Mental Capacity Act, the provisions of which have a direct relevance to DNACPR recommendations. We report on a survey and focus groups that probed the experiences of this professional group during the pandemic. We recruited 262 participants by approaching civil society organisations in which capacity professionals are well represented; twenty-two participated in follow-on focus groups. We used manifest content analysis and descriptive statistics to



any medium, provided the original work is properly cited.

¹Essex Autonomy Project, School of Philosophy and Art History, University of Essex, Wivenhoe Park, Colchester, CO4 3SO, UK

²School of Health and Social Care, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, UK

³School of Law, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, UK
⁴School of Law, Utrecht University, Heidelberglaan 8, Utrecht, 3584 CS, The Netherlands

^{*}Correspondence to Emily Fitton, Essex Autonomy Project, School of Philosophy and

analyse the results. Our findings contribute to an emerging picture of what transpired in residential care homes during the first year of the pandemic and help to provide an empirical and normative basis for the development of the new guidance and training for which the CQC has called.

Keywords: advance care planning, care homes, COVID-19, DNACPR, 2005 Mental Capacity Act

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Introduction

The COVID-19 pandemic brought renewed attention to the so-called 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) recommendations—recommendations, made in advance, about whether to attempt cardiopulmonary resuscitation (CPR) if a person stops breathing and/or their heart stops beating. The ensuing controversy prompted an investigation by the Care Quality Commission (CQC), which identified several concerning practices and potential human rights violations in the use of DNACPRs, and issued a call for new standards, guidance and training (CQC, 2021). But the resulting CQC report had little to say about what the new standards, guidance and training should consist of.

We consider the guidance and training needs of one professional group in particular: those we term 'capacity professionals'. This professional group includes Independent Mental Capacity Advocates (IMCAs), Best Interests Assessors (BIAs) and care home managers. Often coming from a social work background, their professional role requires them to apply the provisions of the 2005 Mental Capacity Act (MCA). Whilst they are not, strictly speaking, best interests decisions, DNACPR recommendations should nevertheless be guided by the legal framework for best interests decisions set out in the MCA (Office of the Public Guardian [OPG] et al., 2022, p. 120). Capacity professionals will therefore often have a critical role to play in the decision-making process—as for example where an IMCA helps to ensure that the person's wishes and feelings, beliefs and values are taken into account. They are also well placed to report on DNACPR practices in care settings, to educate others about the provisions of the MCA, and to report on unlawful or otherwise inappropriate practices if they witness them. In order to play these roles effectively, however, this professional group requires both guidance and training.

In what follows, we supplement the CQC's investigation by reporting findings from an online survey and focus groups. Our aim is in part descriptive and retrospective: We report on the experiences and perspectives of a class of professionals who worked in or with residential care facilities during the pandemic—with a focus on DNACPR practices. But we also look forward. Drawing on our empirical findings, supplemented by normative considerations drawn from existing law and guidance, we identify five areas of concern to be addressed in new policy and training for capacity professionals working in or with residential care facilities. These pertain to (1) individualised versus blanket use of DNACPR recommendations; (2) practices of consultation in connection with DNACPR recommendations; (3) the legal status of DNACPR recommendations; (4) the use of DNACPR recommendations to inform decision-making beyond CPR and (5) challenges to and reviews of DNACPR recommendations. Our recommendations include proposals for revisions to the most commonly used DNACPR forms, which in their current form can foster confusion and reinforce poor practices.

Background

'DNACPR' is an acronym; it stands for 'do not attempt cardiopulmonary resuscitation'. If it is to be successful, CPR must be administered promptly, yet, judgements about whether to perform CPR are complex and high stakes. English law applies a strong presumption in favour of saving life (Re T, 1993) and in the case of cardiopulmonary arrest, there is therefore a presumption in favour of attempting CPR (British Medical Association [BMA], Resuscitation Council UK [RCUK] and Royal College of Nursing [RCN], 2016, p. 17). Nevertheless, CPR is a traumatic procedure. Where a person is dving from an irreversible condition, CPR may be futile, or the benefits minimal and administering it may preclude a peaceful and dignified death (General Medical Council [GMC], undated, para 128). As a consequence, CPR might not always be appropriate (BMA, RCUK and RCN, 2016, p. 2). Individual preferences for CPR also vary. Some have a strong preference that all possible measures to keep them alive should be taken; others may be strongly opposed to the so-called 'heroic measures'. DNACPR forms, which record DNACPR recommendations in advance of an anticipated arrest, are intended to avoid recourse to CPR where CPR would not be in the interests of the patient.

Early in the COVID-19 pandemic, DNACPR recommendations became the focus of intense public scrutiny. Media reports alleged that DNACPR recommendations were being put in place in a manner that violated the existing guidance, which prescribes individualised assessment and consultation. In particular, it was reported that DNACPR forms were introduced into residents' records in a blanket fashion, either for all residents of particular care homes, or for all residents with specific characteristics, such as being of a certain age or suffering from cognitive

impairment (Lintern, 2020; Thomas, 2020). The CQC reported a significant rise in the number of DNACPR recommendations in place for perevidence blanket adoption care. of of **DNACPR** recommendations in some care settings and evidence of DNACPR recommendations being adopted without consultation. It also sounded the alarm about the risk of unlawful discrimination on the basis of age or disability (CQC, 2021; see also British Association of Social Workers, 2020). Whilst the pressures presented by the pandemic no doubt contributed to the proliferation of such practices, many of the issues identified by the COC pre-date the appearance of COVID-19 (see, e.g. Callus, 2018; MacCormick et al., 2018). The CQC's call for new guidance, training and standards provides an opportunity to address those longstanding issues.

Literature review

In considering the legal framework governing these matters, it is important to distinguish two phases in the life of a DNACPR recommendation: (i) the 'making and documenting' of a DNACPR recommendation and (ii) the 'use' of such recommendations to inform subsequent clinical decisions.

Making a DNACPR recommendation

Following two landmark legal cases, Tracey in 2014 and Winspear in 2015, there is a clear duty in English and Welsh law to carry out a consultation prior to recording a DNACPR recommendation. In both of the above cases, DNACPR recommendations were added to the patient's file without consultation. The courts ruled that, unless consultation would be likely to cause physical or psychological harm, failure to consult with respect to a DNACPR recommendation was in breach of Article 8 of the 1998 Human Rights Act (R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors, 2014), and that, where the patient lacks capacity, those close to them should be consulted (Winspear v City Hospitals Sunderland NHS Foundation Trust, 2015). The guidance states that, where no consultation has taken place, the reasons for this lack of consultation should be documented on the DNACPR form (BMA et al., 2016, p. 3). Nevertheless, DNACPR forms continue to be added to patients' files without consultation (CQC, 2021; Bows and Herring, 2022), and there is evidence that confusion persists amongst medical professionals concerning the scope and purpose of consultation (MacCormick et al., 2018).

The form that consultation should take depends upon the grounds on which the DNACPR recommendation is adopted. A DNACPR recommendation may be made either because there is no (reasonable) prospect of successfully reviving the person or on the basis of an assessment that, although there may be some chance of success, the burdens associated with the procedure outweigh the potential benefits (BMA, RCUK and RCN, 2016). The duty to consult applies in both circumstances but the nature of the requisite consultation differs. In the first case, the DNACPR recommendation has its basis in a narrowly clinical judgement, and consultation may principally take the form of informing the person (and relevant others) of the clinical determination, the grounds on which it was made and their right to seek a second clinical opinion. Here, the DNACPR recommendation itself is appropriately taken by clinicians alone (BMA et al., 2016, pp. 10–13).

In contrast, where the basis for a DNACPR recommendation is a judgement about the balance of potential burdens and benefits, a broader range of considerations comes into play. Here, a DNACPR recommendation must take into account the person's wishes, feelings, beliefs and values and consultation should usually be undertaken in order to determine what those wishes, feelings, beliefs and values are (BMA, RCUK and RCN, 2016, p. 13).

In both cases, DNACPR recommendations must be made on a case-by-case basis and should not be applied to groups of people in a 'blanket' fashion (BMA, RCUK and RCN, 2016, p. 9). Under the *2010 Equality Act*, it is discriminatory, and thus unlawful, to base a DNACPR recommendation solely on a person's having a particular disability.

Using a DNACPR recommendation

With regard to their use in subsequent clinical decision-making, it is important to distinguish DNACPR recommendations from advance refusals of CPR, and to note that, unlike the latter, DNACPR recommendations are never legally binding (BMA, RCUK and RCN, 2016, p. 5). An advance refusal of CPR is a type of advance decision to refuse treatment (ADRT), as defined in MCA Sections 24–26. ADRTs are undertaken by the person whose treatment they concern, and are made in anticipation of a future loss of decision-making capacity. They allow a person to exercise, in advance, their right to refuse medical treatment. A valid and applicable ADRT is legally binding. (On the use of ADRTs during the pandemic, see Lyne and Parker, 2020.) DNACPR recommendations, in contrast, are undertaken and recorded by members of the clinical team or other health professionals. They serve as a guide for the clinician who may later be faced with a decision about whether to administer CPR, but

they do not bind that clinician, who must exercise their own clinical judgement.

The COC found that 54 per cent of care home residents with a DNACPR recommendation, and 44 per cent of relatives or carers responding on behalf of such individuals, felt that the DNACPR recommendation had delayed or prevented other medical treatments (2021, Appendix B, fig. 10). Amongst the population of patients already hospitalised with COVID-19, however, Sutton et al. (2021) found that lifesaving treatment other than CPR was administered in roughly the same proportions in those with DNACPR recommendations, as in those without DNACPR recommendations, or with DNACPR recommendations made only at an advanced stage. Legally, it is crucial to distinguish DNACPR recommendations from decisions about other forms of treatment. Forms that record DNACPR recommendations may sometimes record further decisions about end-of-life care, but the DNACPR recommendation itself applies narrowly to the withholding of CPR (BMA, RCUK and RCN, 2016, p. 5). To use a DNACPR recommendation as the basis for denying other life-saving measures, or for the refusal of hospital admission, thus constitutes an unlawful departure from their authorised use.

Review of DNACPR recommendations

Whilst guidance is clear that there should be a review process for DNACPR recommendations (BMA, RCUK and RCN, 2016, p. 30), there is relatively little guidance on what this review process should consist of. Decisions about the duration of a DNACPR recommendation should be made on a case-by-case basis, with some DNACPR recommendations being indefinite (BMA, RCUK and RCN, 2016, p. 30), but review should take place wherever there is a 'substantial change in the patient's clinical condition'; a change in setting; a change in the wishes, feelings, beliefs or values of the person; or where a review is requested by the patient or, where appropriate, their next of kin (BMA, RCUK and RCN, 2016, p. 4). Whilst some DNACPR forms include a field to indicate a review date, the absence of national guidance results in the significant regional variation in review practices (Freeman et al., 2015).

DNACPR and the role of social workers

The existing literature has tended to focus on the role that social workers play in advance care planning (ACP) (Munn and Adorno, 2008; Wang et al., 2018; Pritchett et al., 2021). ACP can take a variety of forms, but is typically a collaborative process in which professionals and family

members work with the care recipient to plan for future care decisions. Conversations about CPR may form part of ACP, but ACP typically has a broader scope and might include, for example, decisions about where the patient wishes to die. Social workers may be involved in supporting the patient in making such decisions (Wang et al., 2018).

In contrast, responsibility for a DNACPR recommendation ultimately lies with the relevant medical professional. Nevertheless, social workers sometimes have a significant role to play in the decision-making process, supporting the patient and those close to them, and advocating for their views and wishes. According to MCA Section 37, an IMCA must be appointed where all three of the following conditions are met: (i) decisions are made about the provision or withholding of serious medical treatment, (ii) the patient lacks decision-making capacity and (iii) there is no other person whom it would be appropriate to consult. Where the DNACPR recommendation takes account of factors beyond the narrowly clinical, the role of an IMCA will be to identify the views, feelings. wishes, beliefs and values of the patient, and to ensure that these are considered as part of the decision-making process (OPG et al., 2007, p. 30). Social workers more generally have a key role to play in ensuring that the rights of care home residents are upheld (Jolly, 2020; Anand et al., 2021). The COC found that 28 per cent of DNACPR recommendations were applied whilst the patient was living in a care home or in supported living (2021, Appendix B, fig. 4) and social workers who work with care homes, such as BIAs, are thus well-placed to identify and draw attention to unlawful practice with respect to DNACPR. Despite the significant visibility of social workers in these contexts, however, there is limited literature exploring the experience of social workers in these roles, and sufficient attention has not been given to the skills and training necessary for promoting ethical practice in this area.

Research aims and objectives

The aim of the present research was to investigate DNACPR practices within care homes during the pandemic; to better understand the role that capacity professionals might play in ensuring the lawful use of DNACPR recommendations in this setting and to consider how these professionals can best be supported in that role. Our objective was to identify key areas of concern for capacity professionals in relation to DNACPR recommendations, around which tailored training, guidance and policy might be developed. This was informed both by existing literature and by an analysis of existing guidance, statute and case law. In particular, we sought to understand: whether participants felt adequate consultation had taken place prior to the making of a DNACPR recommendation; whether they had encountered 'blanket' DNACPR

recommendations; whether and in what ways the presence of a DNACPR recommendation had impacted other forms of treatment and what their experiences were in relation to the review of DNACPR recommendations.

Methodology

The data presented below are drawn from a broader study investigating the impact of COVID-19 on the human rights of residents in care homes in England and Wales (Kuylen *et al.*, 2022).

Research design

Using a sequential explanatory mixed-method design, we conducted an online survey and two follow-on focus groups in the Spring of 2021 (i.e. approximately one year into the pandemic). An explanatory mixed-method design involves the use of qualitative data to explain and understand initial quantitative insights (Ivankova et al., 2006). In the current study, follow-on focus groups were used to explain and elaborate upon quantitative insights derived from the survey. Our methods were aimed towards generating practical insights in response to our study objectives, without adherence to a single philosophical or ontological perspective (Morgan, 2014).

Ethical approval for this study was obtained from the University of Essex Humanities Sub-Committee. A participant information sheet was provided to all participants prior to survey and focus group participation; informed consent was obtained via the Qualtrics platform (for the survey) or email (for the focus groups) prior to data collection.

Sampling and recruitment

We adopted a purposive sampling strategy aimed towards surveying a variety of health and care professionals working in or with care homes during the COVID-19 pandemic. This included professionals involved in direct care provision (e.g. support workers), and external professionals with support and advocacy functions (e.g. BIAs, Deprivation of Liberty Safeguards practitioners). We also sought geographic representation across regions of England and Wales.

A link to the online survey and participant information sheet was sent via email to existing networks of the research team members, including the National Mental Capacity Forum (NMCF) mailing list and two research-practice networks, and shared via social media. At the end of

the survey, participants were asked to provide an email address if they were interested in participating in a focus group aimed at further exploring key topics identified in the survey. To protect anonymity, email addresses were not connected to any survey answers.

Two hundred sixty-two individuals responded to the survey; twenty-two individuals participated in the focus groups. Both the survey and focus groups covered a range of topics; for present purposes, we extract the data that pertain specifically to DNACPR practices. Sample characteristics are provided as Supplementary Material.

Data collection

Survey topics were informed by (i) a scoping review and (ii) analysis of registration data and delegate feedback from a series of 'rapid-response to COVID-19' webinars held in collaboration with the NMCF. Survey questions were developed through discussion amongst members of the research team and seven external partners with expertise across law, medicine and social care. The survey mainly consisted of closed questions, with some opportunities for elaboration in free-text response.

Five focus groups of approximately one and a half hours duration were held online using a video conferencing platform, and transcribed verbatim for analysis. A minimum of four and maximum of six participants per focus group was determined as reasonable for enabling meaningful discussion. The composition of each focus group was determined by both practical considerations of participant and researcher availability, and consideration of the professional backgrounds and roles represented within each group.

The focus group protocol was developed in line with key issues identified by the survey and refined through discussion with the research team. For the purposes of this article, we have extracted data from the DNACPR component of the focus group protocol. We asked participants about (i) the effect of the pandemic on the prevalence and process of adopting DNACPR orders, (ii) the use of DNACPR orders in clinical decision making and (iii) the prevalence and value of forms used to document and record DNACPR recommendations.

Analysis

Quantitative data were analysed with descriptive statistics generated via the Qualtrics survey platform, whilst qualitative data from free-text survey responses and focus group transcripts were extracted into the QSR NVivo platform. Following Bengtsson's (2016, p.10) four-stage process of manifest content analysis, our focus was on the 'visible and obvious'

meaning conveyed by participants, which was considered most appropriate for pragmatically approaching our aim of understanding the reality of professional practices and experiences in care homes during the COVID-19 pandemic.

Members of the research team read through the collated focus group transcripts and free-text survey responses to develop familiarity with the data. Using a deductive approach, initial coding was guided by the existing survey and focus group structure pertaining to DNACPRs. This initial coding resulted in three primary codes (effect of pandemic on DNACPRs; the use of DNACRPs in decision making; forms used to document and record DNACPR recommendations) and several subcodes. These initial codes were then 're-contextualised' (Bengtsson, 2016) by re-reading transcripts to ensure coverage, and agreed through discussion amongst all authors. During the 'categorisation' and 'compilation' stages, sub-categories were further refined and discussed, resulting in the two primary categories explored below. Appropriate quotations for each category were then selected, and all authors reviewed the presented data for consistency and coverage.

Results

Making and recording DNACPR recommendations during the pandemic

One portion of our survey pertained to the process of making and recording DNACPR recommendations for care home residents. We asked whether new DNACPR recommendations had been recorded during the pandemic; why new DNACPR recommendations had been made; whether DNACPR recommendations were made following consultation with the resident or an appropriate person; whether DNACPR recommendations were applied across groups of residents sharing characteristics such as frailty, age or cognitive impairment; and whether and how practice around DNACPRs changed during the pandemic. In focus groups, participants were also asked whether, and why, the pandemic had prompted professionals to rethink practices associated with DNACPR, and their views were sought on the various DNACPR forms commonly in use.

Responses to our survey supported CQC findings regarding DNACPR recommendations in the context of the pandemic. Fifty-six per cent of respondents reported that they had seen new DNACPR recommendations recorded on the files of care home residents during the pandemic. Of these, 45 per cent reported that new DNACPR recommendations were made because the pandemic highlighted the need to consider or reconsider DNACPR recommendations. Respondents also expressed the

view that the increase in DNACPR recommendations during the pandemic was driven by decision-making within hospitals: five respondents reported that DNACPR recommendations were added to residents' files upon admission to hospital and then carried over, or 'left on file', when the person returned to the care home.

Our findings also appear to support CQC findings regarding the absence of consultation. Fifty-five per cent of survey respondents reported that, through their work in or with care homes during the pandemic, they had witnessed DNACPR forms being added without consultation with the resident or a relative. One focus group participant described the process in these stark terms:

there was no consultation with family, no consultations with the person, and, in some instances, not even a consultation with the care home staff. They were just returning with a piece of paper ... that says, 'do not resuscitate this person.' (Advocacy Manager)

In free-text comments, some survey respondents suggested that consultation was considered unnecessary because DNACPR recommendations were seen as strictly clinical decisions taken by doctors. For example, one respondent described a DNACPR recommendation as 'purely a GP-led decision based on the GP's perception of whether the person should be resuscitated' (Facility Management Team Member). Others reported cases where consultation had not taken place because the person lacked capacity but where relatives or IMCAs had not been engaged, or expressed concern that the reasons for a lack of consultation had not been clearly documented. One focus group participant said:

when I see a DNACPR [form], ... I look at the bit where it [asks whether],it's been consulted with the person. And so many times it's just ticked 'no.' And then it will say, the reason why and they'll tick, or they'll write, something such as 'dementia.' (Advanced Practitioner, Deprivation of Liberty Safeguards)

Focus group participants suggested that practices surrounding consultation had deteriorated as a result of operational challenges arising from the pandemic. One participant explained that consultation during the pandemic 'has happened in a very, very fast-paced way, which is why it may feel rushed' (BIA).

Six of the twenty-two focus group participants reported that they had either witnessed or heard about decisions to put in place DNACPR recommendations for all residents of a care home during the pandemic. One participant stated:

we've spoken at length in our team about at least a couple of care homes that I can think of in our area, where at the beginning of the pandemic GPs have gone into the homes and signed off on DNACPR orders for all of the residents. (Social Worker/BIA)

Some participants reported that they were aware of blanket decisions. Of the 55 per cent of survey respondents who reported that they had witnessed DNACPR forms being added without consultation, 28 per cent reported that this was because a decision had been made to add DNACPR forms to the files of all residents of a particular care home; 25 per cent reported that it was because a decision had been made to record DNACPR recommendations in the files of a group of residents sharing particular characteristics such as age, frailty score, dementia or other pre-existing medical conditions. One focus group participant described 'a blanket decision by the GP across the 10 people in the care home, all with learning disabilities and physical disabilities' (Apprentice Social Worker).

The CQC's concerns about discrimination were also shared by participants. One focus group participant reported: 'My overarching feeling is that it was age discrimination, pure and simple' (Social Worker/BIA). Another expressed the concern that decisions about DNACPR were informed by assumptions about the quality of life of persons with learning disabilities: 'I think it was not such an age thing ..., I think it was the quality of life ...: "Oh well, they haven't got much quality of life, let's put in a DNAR [sic] order" (Social Worker/BIA).

Using and reviewing DNACPR recommendations during the pandemic

Seventeen per cent of survey respondents reported that, at some point since the beginning of the pandemic, they had witnessed DNACPR recommendations influence medical decisions beyond CPR. Of these, 31 per cent reported that this continued at the time of our survey, one year into the pandemic. When asked to specify which medical decisions had been influenced by DNACPR recommendations, twenty-two respondents reported that a decision had been made not to transfer any residents with a DNACPR recommendation to hospital. Three respondents reported that medical staff had refused to attend a care home when a resident with a DNACPR recommendation in place required medical attention. Four respondents reported that they had witnessed the denial or withdrawal of medication on the basis that a resident had a DNACPR recommendation in place. This included the refusal of intravenous antibiotics and, in one case, the withdrawal of all medication. In free-text comments, one respondent wrote that DNACPR recommendations are seen as orders not to provide any medical treatment whatsoever: 'Some staff see DNR [sic] as "do not care", or "do not seek any medical treatment" (Other).

Focus group participants affirmed that DNACPR forms have influenced medical decisions beyond CPR. One participant reported that, in

the context of the pandemic, a DNACPR recommendation effectively means that a resident will not be transferred to hospital if they fall ill. The participant said that residents with a DNACPR form had been told, 'You're in a nursing home, you can stay in a nursing home because you're being treated' and went on to observe that, in practice, DNACPR recommendations relate to all forms of medical treatment. A DNACPR is, according to this participant, 'about CPR, but also it's about antibiotics, it's about hospital treatment, it's about fluid, it's about anything that's a sustaining treatment' (Social Worker/BIA). Another participant added that 'it's also sometimes used as a way of managing end of life and whether people want to remain in the care home or be admitted to hospital and I just think it's really badly understood by professionals—some professionals anyway' (Social Worker/BIA).

Seven of the twenty-two focus group participants expressed concern at the lack of a clear procedure for reviewing DNACPR recommendations. One participant observed that a DNACPR 'seems to be like a one-off decision that stays with the person' (Social Worker—Care Home Support Team). According to another participant, this is particularly true for persons discharged from the hospital. The participant reported that, ordinarily, general practitioners (GPs) would review DNACPR recommendations made in the hospital upon return to the care home, but this procedure had not always been followed during the pandemic—and 'Care homes weren't actually even informing the GP that a DNACPR order had been put on the individual':

I had a gentleman who was very fit and healthy, and contracted COVID and ended up in hospital. And within hospital, they implemented a DNR [sic] order, which then carried on to the care home, even though that's not how it works. And so, the care home... they refused to review the DNACPR order, despite my request to do so on several occasions, and even though he had recovered from the things that would have affected his ability to recover. (Advocacy Manager)

In addition to the issues identified in our survey and focus groups, one further area of concern has arisen in the context of CPD training that our team regularly provides to frontline professionals. When asked whether DNACPR recommendations 'are legally binding', only a small minority of capacity professionals are aware that they are not.

Discussion: towards new standards, guidance and training

In answering the CQC's call for new standards, guidance and training, it is worth keeping in mind that existing guidance is generally clear and accessible, and covers many of the essential legal points summarised above

(BMA, RCUK and RCN, 2016), although one notable exception, as Freeman et al. (2015) have documented, concerns guidance for reviewing DNACPR recommendations. As both the CQC's report and our own data make evident, however, clear guidance on DNACPR has not always proven to be effective in ensuring lawful practice. It is therefore important to think about standards, guidance and training as a package, whilst also being alert to factors that may foster misunderstanding or prompt poor practice.

Administrative proformas

A number of our recommendations pertain to the administrative proformas used to record DNACPR recommendations. These forms provide more than simply an administrative record; they send important signals about what a DNACPR recommendation is, and how such decisions should be arrived at and applied. They may be used to structure training, and provide an opportunity to educate professionals and reinforce good practice. Where poorly designed, they also have the potential to mislead or to reinforce poor practice.

Whilst a unified DNACPR form is currently in use for Wales, there is no such uniformity in England (though unified DNACPR policies and forms have been established across some regions). Participants in our study mentioned three different instruments commonly used for recording DNACPR recommendations, referring to them respectively as 'the red form', 'the lilac form' and 'the ReSPECT form'. The first two descriptors refer to the colour of the documents themselves: red forms have a red band around the edges; the lilac form is printed on a lilac paper—though there is considerable variation even within these categories, and particularly amongst the red forms. The ReSPECT form, produced by the National Resuscitation Council, serves a broader purpose, covering an array of issues pertaining to 'ceilings of treatment' and end-of-life planning in addition to recommendations about CPR.

The sheer number of different forms in circulation is unhelpful, and there have been calls for a single standard national form (Health Select Committee, 2015). Of more urgent concern, however, are shortcomings in the existing forms. Three issues in particular merit comment.

First, there is evidence of considerable confusion amongst capacity professionals about whether DNACPR recommendations are legally binding. As we have seen, they are not—but the current forms do not make this sufficiently clear, and arguably convey the impression that DNACPR recommendations are binding. The headings of the red and lilac forms both take the form of an unqualified imperative: 'Do not attempt cardiopulmonary resuscitation'. Even the ReSPECT form, whose heading includes the word 'Recommendation', nonetheless retains this

form of words. Such an instruction, signed by a senior clinician, might understandably be interpreted as conveying a direct and binding instruction. This impression is reflected in, and reinforced by, the common but inaccurate description of these documents as 'DNACPR orders'.

Second, we found troubling indications that DNACPR recommendations are used to inform clinical and care decisions beyond CPR. Existing guidance is generally clear that DNACPR recommendations apply exclusively and narrowly to CPR (BMA, RCUK and RCN, 2016, p. 5). Guidance from the GMC is a notable exception in this respect, including language that might be understood to suggest that DNACPR recommendations play a role in deciding whether a person should be transferred to the hospital (GMC, undated, para 129). Even where guidance is clear, however, terminology has the potential to foster misunderstanding. Particularly problematic is the common truncation of the DNACPR acronym to 'DNAR'-Do Not Attempt Resuscitation. At one training event held by the NMCF in November 2020, registrants (predominantly social care and capacity professionals) were asked whether they had heard the terms DNACPR. DNAR and DNR used interchangeably during the pandemic. More than two-thirds of the respondents (318 of 459) replied affirmatively (NMCF, 2022). Here again, the format of the paperwork reflects, and may reinforce, misunderstanding.

A third area of concern pertains to the issue of who makes a DNACPR recommendation, and who is involved in any associated consultation. As we have seen, when the basis of a DNACPR recommendation is the medical conclusion that CPR will not restart the heart and breathing for a sustained period, clinical judgement is determinative. But in other cases, a DNACPR recommendation involves a broader judgement about whether the potential benefits of CPR outweigh the potential harms. Such decisions may implicate questions about the tolerance of risk or the quality of life that would likely ensue following successful resuscitation. Clinical judgement is undoubtedly relevant to recommendations made on such grounds, but it is not determinative. The present configuration of the red and lilac forms fails to convey this point with sufficient clarity. Moreover, on all the forms we identified, the only signature fields were designated for use by clinicians. Without sufficient emphasis on the importance of consultation, there is a risk that this configuration reinforces the impression reported by participants in our study, namely, that a DNACPR is a 'purely a GP-led decision based on the GP's perception of whether the person should be resuscitated.'

Mechanisms for raising and recording concerns

Many of our study participants expressed unease at the way DNACPR recommendations had been handled in care settings during the

pandemic. As we have seen, concerns were expressed about, inter alia, blanket applications of DNACPRs, failure of adequate consultation, in-adequate or inadequately documented grounds for DNACPR recommendations, and reliance on DNACPR recommendations beyond their designated use. As discussed, social workers have a key role to play in ensuring that the human rights of care home residents are upheld, yet, many of the professionals in our study expressed the view that the DNACPR decision-making process was out of their hands, controlled largely by clinical professionals in hospitals or GP practices. The combination of these factors can understandably lead to a sense of disempowerment on the part of capacity professionals, who may find themselves in the position of witnessing practices that they suspect may be legally incorrect or otherwise inappropriate, but who lack any clear pathway for taking concrete actions in response.

There is no simple solution to this problem, but it is nonetheless important that new standards, guidance and training include strategies for addressing it. Certainly, one important element of a response must be to ensure that new training includes clear guidance about who should be involved in the DNACPR decision-making process, and the circumstances under which it must involve more than a narrowly clinical determination. Training should also focus on the validity and applicability of DNACPR recommendations; the requirements for consultation; and the basis on which a DNACPR recommendation can and should be reviewed.

One strategy for reinforcing such training in the ongoing practice would be to include a dedicated section on the DNACPR form itself in which requests for review can be recorded. An indicative list of grounds for review could also be provided (see Supplementary Material). The incorporation of a review field and accompanying list of grounds on a redesigned standardised DNACPR form would have benefits at three stages. First, for the person making and recording the initial DNACPR recommendation, the form would provide a clear indicator of the grounds upon which a DNACPR recommendation might be challenged, serving as a prompt to reinforce good practice. Second, for anyone with concerns about the validity of a particular DNACPR recommendation, the field would provide a pathway for recording these. Finally, the inclusion of such a field would function as an educational instrument, built into the form itself, clarifying when review is appropriate and projecting the core elements of good practice in this area.

Limitations

Our study was limited by the size and non-representative character of the sample, and by the self-selecting basis for participation. The study lacked any method for verifying the accuracy of reports from participants, or for distinguishing sharply between reports of first-hand experiences and hearsay. Further, the study focused narrowly on the experiences of social care and capacity professionals; the voices and perspectives of medical professionals, care home residents and family members were not included.

Conclusion and recommendations

Taken together, the CQC report and our own study provide ample cause for concern about current DNACPR practices. The concerns did not originate with, but were certainly exacerbated by, the COVID-19 pandemic. Crucially, however, the pandemic also served to shine a light on those practices, creating conditions under which longstanding issues might finally be addressed. The CQC's call for new standards, guidance and training presents an important opportunity for reform. To make the most of this opportunity, attention should be paid to the need for tailored guidance and training for social work and capacity professionals, who have important roles to play in DNACPR practice. New standards, guidance and training for this professional group should focus on five key areas:

Individualised versus blanket use of DNACPRs

New standards, guidance and training should make clear that any DNACPR recommendation must be made on the basis of individualised assessment, and training materials should include case studies to illustrate what such an assessment might look like in a variety of cases. A revised, standardised DNACPR form should clearly articulate the requirement for individualised assessment, provide required fields for recording evidence drawn from such an assessment and include reference to the CQC's warning that the blanket use of DNACPR forms may amount to unlawful discrimination. It should be supplemented with clear guidance about circumstances in which it may be necessary to set aside a completed DNACPR form on the grounds that it lacks evidence of individualised assessment.

Practices of meaningful consultation

New standards, training and guidance should make clear (1) that consultation is always required at the time of a DNACPR recommendation, unless such consultation would be likely to cause physical or psychological harm, and (2) that if consultation with the person is impossible, then

family members, carers, health care proxies or advocates should be consulted. It should make clear the distinction between the two grounds recognised in law for making a DNACPR recommendation: a narrowly clinical judgement that there is no (reasonable) prospect of successfully reviving the person, and a broader judgement about the balance of potential burdens and benefits. It should provide guidance, supported by vignettes, about the form that consultation should take in each of these cases. A revised, standardised DNACPR form should include required fields that report either on specific consultations undertaken or on evidence that consultation would be likely to cause physical or psychological harm. It should be supplemented with clear guidance about circumstances in which it may be necessary to set aside a completed DNACPR form on the grounds that it lacks evidence of legally required consultation (see also Michalowski and Martin, 2022).

The legal status of DNACPRs

New standards, training and guidance should explicitly avoid use of the expression 'DNACPR orders', so as to avoid conveying the false impression that DNACPR recommendations are binding. A revised, standardised DNACPR form should clearly indicate that the form records a recommendation about the use of CPR. Training should be clear about the distinction between DNACPR recommendations and legally binding ADRTs (Michalowski and Martin, 2022).

The use of DNACPRs to inform decision-making beyond CPR

New standards, training and guidance should be clear that a DNACPR recommendation applies only to CPR, and not to any other form of treatment or care. A revised, standardised DNACPR form should explicitly warn against reliance on a DNACPR recommendation in making other care decisions. Existing guidance that might be understood to suggest that DNACPR recommendations should play a role in decisions about transfer to hospital should be revised.

Challenges to and reviews of DNACPR recommendations

New standards, training and guidance should include content that pertains specifically to the review process for DNACPR recommendations, whilst also providing instructions concerning the grounds upon which a review can be requested. A revised, standardised DNACPR form should include a field in which a request for review can be recorded, along with a field in which the grounds for requesting the review can be specified.

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Supplementary material

Supplementary material is available at British Journal of Social Work online.

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