DNACPR decisions: who decides and how?

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1. Introduction

1.1: What is this resource for?

Good clinical practice has at its heart shared decision-making between the clinician and the patient.

Both parties bring their particular expertise or perspective to discussions and decisions about treatment and care - and to plans about how to manage health problems in the future.

Given its close association with death, cardiopulmonary resuscitation (CPR) can present particular challenges in reaching clinical decisions and communicating with patients and those close to them.

These challenges can lead to anxiety and misunderstandings – particularly when they concern Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions.

This web resource aims to explore these issues but it is not intended to be guidance or provide definitive answers. Precision is difficult, given the ethical dimension and differing perspectives around concepts such as best interests and the benefits, burdens and harms of life-sustaining treatment for those near death.

These issues are constantly evolving and developing.

The range of speakers in the associated podcasts reflects the many different perspectives.

Additionally, at least two cases testing DNACPR decision-making and policy were before the courts or being prepared as this resource was being prepared.

Quite rightly, this resource does not seek to impose its own interpretation of the law surrounding those issues, nor seek to predict the decisions that the Court will make or set out what it the law should be. It is not designed to provide legal advice and this publication does not necessarily deal with every aspect of CPR and decisions in relation to CPR.

Nor does it prescribe specific actions or approaches.

Instead, it is hoped the resource will encourage discussion and analysis of the complexities and different perspectives that surround existing guidance and legislation.

It also signposts readers to existing guidance and examples of useful tools or documentation.

We anticipate that this resource will be updated in response to any rulings in the legal cases mentioned above and in the light of changing professional and public attitudes and perspectives.

1.2: Who is this resource for?

This resource is predominantly for clinicians involved in CPR decisions, policy-makers and those responsible for clinical governance.

However, it approaches the challenges from the patient's perspective as well as the clinician's. It emphasises the principles of partnership and shared decision-making between a patient and the healthcare team.

Patients and representative organisations may therefore also find it of use.
2. Cardiopulmonary resuscitation – the development of CPR and issues around its use

2.1: CPR

CPR is an emergency treatment that can sometimes re-start the heart and circulation of blood and/or breathing following a cardiac and/or respiratory arrest.

It has been described as a way of re-starting hearts ‘too young to die’ but also restarts lung function.

It is impossible to prevent the heart from stopping as part of the dying process and pointless trying to do so. However, it may be possible to re-start the heart repeatedly when it has stopped repeatedly due to a reversible event, such as a disturbance in rhythm.

A cardiac arrest occurs if the heart stops beating. A patient has had a respiratory arrest if the lungs stop working.

When both the heart and/or lungs respectively stop working the patient has had a cardiorespiratory arrest (CA).

This resource uses the three terms interchangeably.

CPR might include:

- Repeatedly pushing down firmly on the centre of the chest – compressing it by at least 5cm 100-120 times per minute
- Using electric shocks to try to re-start the heart and injecting various medications
- ‘Mouth-to-mouth’ breathing or, where possible, inflating the lungs through a mask over the nose and mouth or tube inserted into the throat or windpipe.

Defibrillation (attempting to re-set the heart rhythm with a DC electrical shock) was first used to re-start a human heart in 1947.

Alongside other elements of CPR, it has been a standard part of coronary care and cardiac surgical practice since the 1960s.

CPR was a major driver to the development of coronary care units (CCUs).

The rapid delivery of CPR and defibrillation in CCUs improved survival rates amongst patients who had a myocardial infarction (heart attack).

In more general settings it was recognised that, whilst CPR was appropriate to try to prevent avoidable deaths, it was not appropriate for people who were at the end of their life because of irreversible medical conditions.

2.2: Respiratory arrest alone

Certain illnesses, such as those that may affect the breathing centre in the nervous system or the function of the respiratory muscles directly, can lead to difficulties with breathing when the heart itself is healthy.

A number of such diseases are present since birth or develop during childhood and adolescence. They therefore threaten a premature death for young people with healthy hearts.
Other neuromuscular diseases in later life may have a similar effect.
A respiratory arrest alone in such people may only be temporary and resolve spontaneously if artificial support is provided to maintain breathing whilst, for example, the neurological drive to breathe recovers.
In other cases it can be reversed easily and successfully if the underlying trigger, such as respiratory infection or muscle fatigue, is treated.
For this group of people, decisions about CPR may vary according to the immediate problem.
If there is just respiratory arrest, the clinical recommendation may be for full and active management, even if the person is nearing the end of their life. If the heart has stopped as well, it might be decided to withhold CPR to allow that person a natural death.
Finally, it is possible for anyone to have a temporary respiratory arrest that could be relatively easily reversed. This can occur because of choking caused by food or medication obstructing an upper airway.
It seems common sense that a respiratory arrest from this should be reversed if at all possible even if someone has a valid decision not to attempt CPR in place and is close to the end of life, not least because it is very distressing.
Ideally, in discussing a possible DNACPR with a patient, the clinician would raise such possibilities to achieve clarity.
In clinical practice it is very unusual for a person who refuses CPR in advance to also refuse attempts to reverse choking as well.
Where this is a real possibility a person may want it recorded in an emergency healthcare plan (EHCP) alongside a DNACPR form. Examples of EHCPs can be found here. Documentation for CPR and related care and treatment is discussed here.

2.3: Misconceptions about CPR and DNACPR
Over recent decades high profile controversies and the mainstream media have helped create and foster significant misconceptions about CPR and the scope and application of DNACPR decisions.
The portrayal of CPR in popular culture such as films and television often gives an unrealistically positive picture of its success and impact.
The likelihood of CPR successfully restoring life ranges from almost nil to around 60%, depending on a number of factors beyond the background health and fitness of the person. These include the underlying cause and type of heart disturbance and the availability of specialist expertise and equipment (such as defibrillators) at the scene of the arrest.
Consequently these highest success rates occur in settings such as coronary and intensive care units. They would not be achieved for people who have arrests in the street.
In June 2012 the respected National Confidential Enquiry for Patient Outcome and Death (NCEPOD) commented on these unrealistic expectations and their impact on clinical decisions in its report on the use of CPR in hospitals (Ref 1).
It said: “The public believes that patients have a 50:50 chance of surviving (a CA), where the professionals accept that survival to discharge is less than 15% (Ref 2). Nor does public appreciation factor in the chance that survival will often involve disability.

“Professionals may know otherwise, but they rarely find the opportunity to articulate that knowledge and when they do they frequently do not take sufficient account of the morbidity involved in their assessment of the prospects of success.

“In short, too many of us have drifted into an expectation that death will provoke a physical intervention as part of a last ditch attempt to prolong life.”

“As a result the professions fail to give an appropriate priority to their obligation to deliver the objects of the exercise, ‘the ceilings of treatment’.”

This web resource discusses data on CPR outcomes here.

Patients, those close to them and the wider public sometimes also believe that a DNACPR decision means the withdrawal or withholding of other forms of treatment or even basic care and support.

This is untrue.

A clinical decision in advance not to attempt CPR in the event of an arrest only applies to attempts at restoring circulation or breathing.

Such decisions do not decide the suitability of any other type of treatment, and never prevent the administration of services to provide for basic comfort and healthcare needs.

Any decision about an incapacitated patient must be made in the patient’s best interests and must never be motivated by a desire to bring about the patient’s death.

The web resource identifies several key elements that will help professionals fulfil their responsibilities and address some of these misconceptions by improving public understanding of this sensitive area of care.

These are brought together in the Reflections section.

2.4: A treatment touched by controversy

Clinicians recognise that, whilst CPR is appropriate to try to prevent avoidable deaths, it is not appropriate for people who were at the end of their life because of irreversible medical conditions.

Inevitably there are sometimes differences of opinion between clinicians and patients about when that point has been reached and it is appropriate to reach a DNACPR decision.

DNACPR is one of very few decisions made by a doctor to withhold or withdraw a treatment that is subject to policy and procedure – with dedicated documentation.

Sometimes clinicians decide that telling a patient about a DNACPR decision would place an inappropriate burden on them, causing them serious harm. This is a highly sensitive matter. In all but the most exceptional cases the clinician should seek to discuss the issue with the patient.

An NHS trust’s alleged failure to inform a patient with Down’s syndrome and dementia – or those close to him – that clinicians had decided not to administer CPR, should it be
necessary, has led to a legal challenge currently before the courts. In that case, the family is also challenging the actual DNACPR decision.

Decisions not to attempt resuscitation on certain patients - and the justifications behind them - came under particular scrutiny in the UK in 2000. A 67 year old woman with cancer and severe infection saw a 'do not resuscitate' decision on her medical notes after she was admitted for treatment.

The matter had not been discussed with her or her family.

The subsequent media debate highlighted concern that decisions around life-sustaining treatment were being taken without adequate discussion with the patient even where they had capacity.

This highlighted the absolute importance of advance care planning wherever possible. This should provide the patient with the opportunity to state their wishes and preferences around future treatments to sustain life.

During such discussions, clinicians should also seek the patient's views about whether they would want to be informed if, at some future point, clinicians decided that a treatment such as CPR would not be successful and therefore would not be attempted.

To provide a genuine refusal to engage in such conversations, the patient would need to be given some basic information about such treatments.

2.5: Written guidance and support for clinicians

The General Medical Council (GMC) published wide-ranging guidance, Treatment and care towards the end of life: good practice in decision-making, in 2010 (Ref 3), It is available here.

We refer to this guidance several times in this web resource.

In 2001 the Resuscitation Council (UK) joined with the British Medical Association (BMA) and the Royal College of Nursing (RCN) to publish a joint statement on CPR decision-making.

The joint statement identified key ethical and legal issues that should inform all CPR decisions. The statement provided general principles that allow local CPR policies to be tailored to local circumstances.

Six years later, in 2007, the three organisations published a revised statement (Ref 4).

This is called Decisions relating to cardiopulmonary resuscitation: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing.

We refer to this as the 2007 Joint Statement through the rest of this resource and it is available here.

2.6: The 2007 Joint Statement main messages

The 2007 Joint Statement outlined ten main messages. Local policies on CPR decision-making should comply with these points. They are:
1. Decisions about CPR must be made on the basis of an individual assessment of each patient’s case.
2. It is not necessary to initiate discussion about CPR with a patient if there is no reason to believe that the patient is likely to suffer a cardiorespiratory arrest.
3. Where no explicit decision has been made in advance there should be an initial presumption in favour of CPR.
4. If CPR would not re-start the heart and breathing, it should not be attempted.
5. Advance care planning, including making decisions about CPR, is an important part of good clinical care for those at risk of cardiopulmonary arrest.
6. Communication and the provision of information are essential parts of good quality care.
7. Where the expected benefit of CPR may be outweighed by the burdens, the patient’s informed views are of paramount importance. If the patient lacks capacity, those close to the patient should be involved in discussions to explore the patient’s wishes, preferences, beliefs and values.
8. If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision refusing CPR, this should be respected.
9. A Do Not Attempt Cardiopulmonary Resuscitation (DNA(CP)R) decision does not override clinical judgement in the unlikely event of a reversible cause of the patient’s respiratory or cardiac arrest that does not match the circumstances envisaged.
10. DNA(CP)R decisions apply only to CPR and not to any other aspects of treatment.

2.7: The impact of the term DNACPR

Some clinicians and members of the public view the phrase Do Not Attempt Cardiopulmonary Resuscitation as being cold and clinical in a pejorative sense.

One lay commentator said that it could seem “like abandonment and a death sentence” (Ref 5).

A clinician’s conversation with a dying person about the futility of attempting CPR should therefore include reassurance that the decision is not about abandonment, but to allow a natural death in the patient’s best interests with a clear discussion of the pros and cons of attempting CPR.

The phrase “Allow Natural Death” (AND) has been suggested as a kinder and more sensitive alternative. However, it is not an appropriate term.

The terms are not interchangeable.

Allow Natural Death has the very significant drawback of ambiguity. It could permit the withdrawal or with-holding of any treatment, such as antibiotics, no matter how beneficial.

DNACPR applies only to one specific treatment that relates to a specific event.

In specific circumstances or settings the term DNACPR could be followed by an explanatory phrase such as ‘to allow a natural death’. This would explain what is intended by a DNACPR decision.
However using AND as a substitute for DNACPR is not recommended as it is unsafe, ambiguous and imprecise (Ref 6). The BMA came to the same conclusion at its 2012 annual conference.

Furthermore, the general law (and the MCA) allows patients to refuse specific treatments. Neither patients nor doctors can predict the outcome of CPR but they can control the decision whether to attempt CPR or not. The phrase “Allow Natural Death” is focussed on the outcome – not the intervention.
3. Making CPR and DNACPR decisions

3.1: The need for early discussion and advance care planning wherever possible

A person’s best interests go beyond just medical opinion. They are not what the professional believes them to be, but what the person would have chosen were they capable.

The assessment of best interests will therefore be easier if the patient has provided input ahead of time through advance care planning and they have been involved in regular discussions as or when circumstances change.

When they become acutely ill or are approaching the end of their life, many people experience varying levels of capacity.

Therefore it is necessary to talk about the individual’s wishes around both present and future care options. Discussing what the individual might wish to happen should they become incapable might initially be uncomfortable but it is necessary to comply with the principles of legislation and guidance.

Such discussions empower both the individual and the clinician and establish a true partnership.

No-one who has a cardiorespiratory arrest (CA) is in a position at the time to consent to - or refuse - an attempt at CPR because they will be unconscious. Therefore, how clinicians make decisions at the time - or support patients to make a decision in advance - lies at the heart of good and safe practice.

There will continue to be emergency situations where no information is available on a patient’s wishes or preferences. However clinicians should work with patients or those close to them or their representatives to minimise the number of such cases.

3.2: Assessment failures in emergency hospital admissions

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD 2012) concluded that patients admitted in an emergency often go on to receive CPR inappropriately following a CA.

The report identified significant failures at the admission stage and in the days after admission. These centred on a failure to assess the likelihood of a patient having a CA and to discuss and decide their CPR status on admission.

These shortcomings were frequently exacerbated by the lack of consultant assessment or review in the hours and days that followed admission.

The NCEPOD 2012 report brought together information on the care and assessment of patients who died despite the administration of CPR after being admitted as emergency cases.

NCEPOD advisors found that the patient’s CPR status was recorded in only 22% of the cases, all of which were acute admissions.

A decision on whether CPR should be attempted if an arrest occurred was taken on admission in only 10% of cases.

Advisors felt that DNACPR decisions should have been documented in a further 20% of cases.
NCEPOD Chair Bertie Leigh outlined the consequences in a strongly-worded foreword to the report.
He said: "A failure – or unwillingness – to recognise the patient being admitted was in danger of arrest meant resuscitation was inappropriately attempted “in many of these cases”.

3.3: A reluctance to engage?
Concerns regarding decisions (or the lack of them) about CPR status accounted for the largest number of deficiencies identified in handling the acute admissions studied by the NCEPOD advisors for their report.

The report challenged all health professionals involved in the management of acute admissions to ensure that decision-making about CPR is applied consistently and communicated effectively.

In his foreword to the report, NCEPOD Chair Bertie Leigh suggested that the failure to assess and reach a decision on CPR in the overwhelming majority of cases studied suggested the problem “may be cultural rather than the product of a deliberate decision in each case”.

Although some case reports claimed there had been no opportunity to raise the issue with the patient, Leigh said his advisors “struggled to reconcile (this claim) with some of the intervals that elapsed between admission and the arrest.

He continued: "The GMC recognises that CPR should be administered in an emergency but it is not good medical practice to fail to anticipate the needs of the patient before an emergency arises."

The enquiry advisors found that “in a substantial number of cases resuscitation was attempted when they thought a DNACPR decision should have been made earlier”.

The report recommended: "CPR status must be considered and recorded for all acute admissions, ideally during the initial admission process and definitely at the initial consultant review when an explicit decision should be made in this group of patients and clearly documented (for CPR or DNACPR)."

3.4: A policy and legal shift towards patient involvement in decision-making
Generally, clinicians can no longer make decisions about people’s treatments and care without, wherever possible, involving them.

They have a duty of care to work in partnership with patients to understand their wishes and act in their best interests. This means delivering health benefits while avoiding excessive risk, burden or harm.

The Mental Capacity Act 2005 (MCA) (ref 7) consolidated and codified existing Common Law around the principles of establishing capacity and a person’s best interests should they be incapable of making a decision on a specific issue.

In his foreword to the Code of Practice (Ref 8) accompanying the Mental Capacity Act, the then Lord Chancellor, Lord Falconer, said:
“It (the Act) will empower people to make decisions for themselves wherever possible, and protect people who lack capacity by providing a flexible framework that places individuals at the very heart of the decision-making process.

“It will ensure that they participate as much as possible in any decisions made on their behalf, and that these are made in their best interests.

“It also allows people to plan ahead for a time in the future when they might lack the capacity, for any number of reasons, to make decisions for themselves.”

The spirit of the legislation is part of a new impetus towards planning care in advance. That impetus has been boosted with the NHS Constitution, the Health and Social Care Act 2012 and associated guidance.

This body of legislation and guidance provides the legal framework professionals must use when helping individuals to make treatment decisions in advance for a time in the future when they may have lost capacity.

Section 4 of the Mental Capacity Act (2005) outlines how they should make decisions in what is believed to be the best interests of a person without capacity based on the individual’s known wishes, preferences, beliefs and values.

The key principles outlined in Part 1 of the MCA are particularly relevant to the capacity of the individual to be involved in CPR decisions.

These are:

- A person must be assumed to have capacity unless it is established that they lack capacity. This assumption might apply only to particular decisions or at a particular point of time in an individual’s care
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
- A person is not to be treated as unable to make a decision merely because he or she makes an unwise decision. (This includes decisions with which others may feel uncomfortable, such as refusal of a clearly life-prolonging or life-enhancing treatment)
- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action.
- In determining a person’s best interests, section 4 of the MCA requires the professional(s) involved to consider “so far as is reasonably ascertainable”:
  - The person’s past and present wishes and preferences (and, in particular, any relevant written statement made by them when they had capacity)
  - The beliefs and values that would be likely to influence his decision if he or she had capacity
  - The other factors that they would be likely to consider if they were able to do so.

3.5: Informing the patient of the physical reality of CPR as part of decision-making

Both successful and failed CPR attempts involve trauma.
The major risks associated with CPR, like any other invasive and potentially harmful treatment, must be made known to patients if CPR is an option for them. This will allow patients to consider the potential risks, benefits and burdens for themselves.

The process is physical and undignified and usually means the person has to be handled roughly. The physical effects of compressing the chest, especially for someone with fragile bones, may be serious.

It is not uncommon (Ref 9) for patients to have ribs or their sternum broken and some may experience damage to the liver, lungs or heart. Occasionally, these injuries would be enough to cause death even if the heart is re-started or breathing restored (Ref 10).

This is another reason why clinicians, whenever possible, should know in advance the wishes of any patient at significant risk of cardiorespiratory arrest.

3.6: Personal choice

Every person’s experience of health and illness is unique: some call it their “journey”. This journey will involve many decisions and dilemmas about treatment options on which they will be advised and supported by their healthcare team.

Every decision about CPR, like any other, is part of this journey in the context of that person’s individual circumstances, needs and wishes.

Each person will reach a point where there are no further treatments to improve their physical health and prevent deterioration and death.

Given the opportunity in advance, patients may refuse to have CPR if it is offered to them. This may amount to an Advance Decision to Refuse Treatment by the patient if the criteria of the MCA are met.

Decisions to refuse CPR in advance are taken most commonly by people with progressive disease(s), multiple significant health problems and increasing frailty.

Some people at significant risk of CA, even when they may respond to attempts at CPR, may choose to refuse it and should be given that opportunity. This is discussed later in relation to advance decisions to refuse treatment (ADRT) and elsewhere.

Many people may choose not to receive CPR while continuing active treatment for their other health problems. Many, but not all, of those in this group are people with multiple chronic health problems.

Some might decide that if a reversal of the cardiac arrest could result in worse circumstances - for example, complete loss of independence - they would rather it was not attempted.

Others may see the postponing of death to be the ultimate benefit confronting the ultimate harm. Yet everyone is eventually faced with the fact that we are all mortal (Ref 11).

Even after discussing the risks of CPR, some patients might consider it worthwhile when the chances of success are less than 5%.

They may be unwilling to regard death as unavoidable unless CPR has been tried and failed. Any patient who wishes to discuss a DNACPR decision is entitled to an explanation of the
clinical duty to avoid imposing harm on patients through treatments that have no chance of success.

These decisions are a matter of personal choice for the patient and must be respected.

3.7: Supporting the patient to make a decision

High levels of risks, burdens and harms modify the level of benefit that we would accept as making a treatment worthwhile.

Assessing a person's functional state and stage of disease is essential when discussing whether any intervention, including CPR, is appropriate.

This prevents treatments such as CPR being applied routinely on people when it will not benefit them and may actually increase or prolong their suffering. It may also be against their wishes.

When there is a general public perception that some particular treatment is always worth trying, clinicians must be willing to answer questions and explain their reasoning.

For example, a person with cancer may wonder why it cannot just be cut out. The patient will need the doctor to explain about their particular cancer and their own situation.

CPR is no exception. As noted above, patients can express a wish not to be involved or informed about such decisions.

However, as noted elsewhere, except in the most exceptional circumstances they must understand that they are being offered the opportunity to discuss a DNACPR decision.

The requirement to inform a capable person or those close to a person without capacity is the subject of a legal case as this web resource is being prepared.

The same ethical and legal principles apply to CPR as to all other treatments.

CPR must be seen in the general context of the clinician’s duty to gain consent in discussion where a treatment may succeed and to communicate and explain why a treatment is not offered when it will be pointless or clinically inappropriate.

If there is any doubt as to whether CPR should be administered, the initial presumption should be in favour of preserving life.

Clinicians may assume that patients with progressive conditions or multiple co-morbidities would not want CPR. However, the presence of those conditions should not lead to assumptions about what patients do and do not want.

In one survey of UK cancer patients, 58% said they would want resuscitation to be attempted despite being told of the poor survival rates (Ref 12).

The 2010 GMC guidance explores the nature and content of a discussion with a patient making a decision where CPR might be successful (GMC 2010). The guidance emphasises the need to:

- Offer the patient opportunities to discuss whether they wish CPR to be attempted
- Adopt a sensitive approach - the patient should not be forced into a discussion
- Provide accurate information about the burdens and risks including the likely clinical outcomes (including whether other intensive treatments and procedures that might
be required will be seen as clinically appropriate after CPR – e.g. prolonged support for multi-organ failure)

- Explain sensitively any doubts the healthcare team has about whether the burdens and risks would outweigh the benefits.
- Provide information on likely length of survival and level of recovery.

3.8: A DNACPR decision for an incapacitated patient

A DNACPR decision should be made for an individual who does not have capacity only if the decision is believed to be in their best interests (as defined by the MCA). It must never be motivated by a desire to bring about the patient’s death.

Whenever possible, professionals should seek to establish the incapable person’s wishes, preferences, beliefs and values by talking to those closest to the individual and/or the person with LPA or an Independent Mental Capacity Advocate (IMCA) before making a DNACPR decision.

The input of the family or others close to the patient lacking capacity should be based on what they believe the patient would have wanted – not their own wishes.

It should also reflect current circumstances – ie what the patient would have wanted at that time given the circumstances they faced.

If the patient lacks capacity to make a decision but is able to provide input that contribution should be respected.

Clinicians should tell the people closest to the individual lacking capacity if they reach a DNACPR decision and explain the reasons to them.

The requirement to inform a capable person or those close to a person without capacity is the subject of a legal case as this web resource is being prepared.

Organisations should acknowledge that often this will not be possible in an emergency. They need to support clinicians who frequently face situations where they have to make CPR decisions for severely ill people who are at risk of having a cardiac arrest at any moment.

Often this will be at night or during the weekend when it is frequently difficult to contact an IMCA. The MCA itself recognises this and says that serious medical treatment can be provided as a matter of urgency when it is not feasible to instruct an IMCA.

If there is a dispute as to an incapacitated patient’s best interests when CPR is to be withheld or withdrawn then the patient or those close to them should be offered a second opinion.

In the relatively rare circumstances where the patient or those close to them continue to fundamentally disagree with the clinical team, legal advice should be sought and the courts can be asked to intervene where there is time to do so.

3.9: The 2007 Joint Statement’s impact on meeting the needs of groups of patients

In relation to CPR, it is evident that the 2007 Joint Statement’s message effectively asks clinicians to decide into which of three groups a patient falls.
Group 1: Those for whom there is no reason to believe a cardiorespiratory arrest is likely. In such cases:

- There will be a presumption in favour of CPR
- There is no need to initiate discussion about CPR unless the patient requests it or the patient has a relevant advance decision to refuse treatment (ADRT).

Group 2: Those for whom an arrest is possible but an attempt to resuscitate would be unsuccessful:

While the 2007 Joint Statement does not set a principle of disclosure, it does make clear that for this group of patients a DNACPR decision documents the fact that CPR will not succeed. This means:

- Some patients will want to discuss this reality as part of communications about end of life.
- For many, however, CPR is irrelevant and other issues are more important
- Where a patient has indicated they would not wish to discuss death and treatments that will not succeed, as outlined above, it would not be appropriate to tell them of their DNACPR status, particularly if it will impose a significant burden.

However the patient must have been clear about the issue that their clinician was wishing to discuss with them – that is, attempted resuscitation from a CA.

If they decide against informing the patient, clinicians must record their reasons in the patient’s health record.

There is a view that in exceptional circumstances where being informed of a DNACPR decision would cause a patient with capacity serious harm a clinician may decide against testing whether the patient wishes to discuss it.

An NHS trust’s alleged failure to inform a patient with Down’s syndrome and dementia – or those close to him – that clinicians had decided not to administer CPR, should it be necessary, has led to a legal challenge. In that case, the family is also challenging the actual DNACPR decision.

See our discussion about withholding information from the patient at their own request or because it will impose a significant burden.

When hospital or hospice patients in this group are discharged home, a DNACPR decision will need to be explained to them and a form placed in their home. Alternatively, as noted elsewhere, the discharging clinicians could share the information with those close to them in line with the GMC’s 2010 guidance.

DNACPR decisions relate solely to CPR and do not affect the administration or provision of any other treatment or care. However, those close to the patient can share the DNACPR form with the paramedics or other clinicians responding to an emergency at home. This will shape the clinical response.

This could help to prevent inappropriate interventions or readmission.

There is an added challenge, however, when patients who are accept the DNACPR decision, refuse to have a DNACPR form at home. Whilst entitled to do that, they must understand that this does place them at risk of an inappropriate attempt and its consequences.
Group 3: People likely to have an arrest and where CPR could be successful. In such cases:

- The patient’s views are paramount
- They should have the opportunity and information to consent to - or refuse - CPR regardless of whether the expected benefit may be outweighed by the burdens or the benefit is likely to vastly outweigh the risks and burdens
- When patients do not have the capacity to consent, the decision must be made according to the best interests process of the MCA 2005 as described elsewhere in this resource.

3.10: The difference between a DNACPR decision and an ADRT

DNACPR decisions should be reviewed frequently when caring for those with progressing and terminal diseases as each person’s wishes are individual and may change frequently. It can also be suspended or cancelled as circumstances change. For example, a DNACPR decision will often be suspended during surgery.

The DNACPR form represents a considered and authoritative opinion that has been discussed by the clinical team as a whole. In many cases it will record the wish of a patient (or those close to them) that CPR should not be attempted.

However, very occasionally an attending clinician would rightly consider attempting CPR despite the presence of a form recording a DNACPR decision – as long as it was not part of an ADRT.

This would only be a factor, as the 2007 Joint Statement says, "...in the unlikely event of a reversible cause of the patient’s respiratory or cardiac arrest that does not match the circumstances envisaged".

In such cases, if the decision appears to set out a clear indication of the patient’s wishes it should be at the forefront of clinicians’ minds when making a best interests decision if the patient is unconscious.

For patients to be reassured that their decisions are legally binding, such decisions have to be recorded as part of a valid and applicable ADRT. Simple refusal is an option but it does not have the same legal status as an ADRT.

In England and Wales, the MCA says that an ADRT refusing CPR “will be valid and therefore binding on the healthcare team if:

- The patient was 18 years or over and had capacity when the decision was made
- The decision is in writing, signed and witnessed
- It includes a statement that the advance decision is to apply even if the patient’s life is at risk
- The advance decision has not been withdrawn
- The patient has not, since the advance decision was made, appointed a welfare attorney to make decisions about CPR on their behalf
- The patient has not done anything clearly inconsistent with its terms
- The circumstances that have arisen matched those envisaged in the advance decision.
However, while the attending clinician at a CA makes their own judgement at the time, he or she will need to have valid reasons to attempt CPR when the patient had been involved in reaching a documented DNACPR decision.

The clinician undertaking the resuscitation will need to record their justification, and possibly defend it, as being in the patient’s best interests even though this went against that individual’s previous agreement.

Where a patient has refused CPR through a valid and applicable ADRT, it is legally binding. The clinical team is required to respect the patient’s wishes.

Clinicians will often face ambiguity.

For example, should the patient's wishes always be complied with in the following circumstances?

A person has made an informed decision that they would not want CPR under any circumstances and communicated that decision verbally to clinicians several times in a clear and lucid fashion. These wishes have been recorded clearly in their health record, including completion of a DNACPR form.

Unfortunately, the clinician who had these discussions with the patient did not advise them to make an ADRT. The patient, while capable, was deteriorating rapidly and this lack of time was also a factor in the failure to make an ADRT.

Is there a legal obligation to respect the patient’s clearly expressed and documented wishes no matter what the circumstances of the arrest?

Some would say yes.

They would compare it to a fully informed Jehovah’s Witness with capacity who verbally refuses a blood transfusion without completing a written ADRT.

Administering a blood transfusion to such a patient may be considered battery.

There has been no similar test case for DNACPR.
4. Organisational approaches and policies

4.1: The impact of differences in organisational approaches and policies

NHS and other organisations have different policies, approaches and documentation regarding CPR. This is particularly relevant to the issue of documentation and when a patient is being transferred between settings, both of which are discussed further here.

The Department of Health’s 2008 national End of Life Care Strategy (Ref 16) said: “DNACPR decisions are an important element of care, which may be elicited through (advance) care planning discussions with people about their wishes and preferences for future care and treatment.

“Policies between Trusts may not always be consistent. This can have implications for ambulance services that may serve several Trusts. This can impact, for example, on how DNACPR decisions are implemented when people are transferred between hospitals, to other service providers, or to their homes.

“Representative bodies for service providers, including Ambulance Trusts, care homes and Hospital Trusts, may wish to explore how they can work together to put resuscitation policies into practice that best meet patients’ needs.”

Ideally, organisations, clinicians and local interest groups should strive to formalise local and regional agreements that are implemented by the governance structures of each organisation involved in an individual’s care.

The 2007 Joint Statement already offers a set of key messages and is a key foundation upon which local policies can be built. This offers a way to minimise variations between local institutions and maintain the consistency and continuity that reassures patients, carers and clinicians and reduces confusion and distress.

The GMC’s 2010 guidance is also an important source of information. It was based on wide public consultation, detailed legal advice and doctors are required to follow it.

The National Council for Palliative Care gives a comprehensive overview of direct relevance to end of life care in applying the appropriate principles of the MCA 2005.

Decisions regarding CPR should also be seen in the broader context of care planning and ACP that reflects the complexities and particular needs of each patient.

This can be reflected in local policies and documentation and help to reduce the impact of variation.

The GMC’s 2010 guidance reinforces the view that doctors should follow this approach as a matter of routine and good practice in care planning.

Professional bodies should consider addressing this question further at a national level.

After all, CPR decision-making and communication come down to clinicians’ professional duties of care.

Possible solutions might include:

- Extension of the GP’s role in contributing to decision-making across organisational boundaries
- Clear processes for identifying the senior responsible clinician according to their role in the patient’s care. This will help ensure that the responsibilities for global
decisions such as CPR move between teams or across settings as the patient moves

- Being explicit about procedures for clinical handover of the senior responsible clinician role.

The senior responsible clinician is likely to change when the individual is transferred between:

- Teams within an institution for various reasons that may be organisational or due to a change of clinical circumstances
- Hospital, hospice or other care facility and home, in either direction
- Two healthcare facilities.

During the transfer itself, the paramedics or ambulance technicians involved must also be aware of DNACPR or ADRT instructions and be clear about:

- Their required actions should the person’s heart or breathing stop during transfer
- What is to be done with the person’s body should death occur during transfer
- Who is to be notified should the person die during transfer.

4.2: The benefits of shared approaches to CPR decisions

Organisations involved in caring for patients who may require CPR could:

- Establish consistency, clarity and quality in local policies
- Establish mutual recognition of policies locally and regionally and encourage shared approaches between organisations that work together
- Overcome concerns about governance that may impede this
- Develop and agree a form of documentation that is recognisable and applicable in all care settings
- Ensure decision-making processes and documentation that are sufficiently flexible to relate specifically to the individual person’s needs and ensure effective care at any time.

Shared or consistent documentation, educational support and appropriate guidance across different organisations and sectors at local level will improve care and promote respect for people’s wishes.

As well as applying to NHS health organisations, this uniformity of approach and support at a local level should extend to social care, hospices, care homes, extra care housing and independent hospitals. It would also provide clarity to coronial and police authorities.

A consistent understanding, agreement and approach amongst this range of organisations and professionals can lead to:

- A reduction in the number of inappropriate CPR attempts
- A reduction in the risk of clinically inappropriate DNACPR decisions being made or applied
- An improvement in the communication of decisions amongst staff and between staff, patients and those close to them
• Greater co-ordination, use and recognition of uniform documentation to limit unnecessary intrusion by attending professionals at the time of an expected and natural death
• An opportunity for ambulance services to support patients as they die without being obliged to attempt resuscitation or transfer to a hospital emergency department
• A consistent response from all sectors when a patient with a DNACPR form dies in transit; one that maintains dignity and spares relatives unnecessary distress
• A rise in a patient outcome measure such as a sense of dignity and family satisfaction.
5. Communication and advance care planning

5.1: Communicating a DNACPR decision to a capable patient

Patients cannot demand CPR if the clinical team feel it would be unsuccessful or impose significant harms and burdens.

They do need, and are legally entitled to, an explanation as to why it is not an option.

Such discussions can be difficult because they obviously involve acknowledging that the patient is nearing death.

Additionally, in such circumstances the clinician is explaining a considered decision rather than offering a choice.

Seeking consent is about choices and options for CPR in those for whom it might be successful. Communication in a case where CPR would not be appropriate involves the clinician explaining why a treatment, such as CPR, would not be suitable. Obviously it would also involve the clinician listening to and responding to the patient’s concerns.

These issues must be weighed up when considering the appropriate level and detail of communication.

The GMC 2010 guidance notes that when the benefits, burdens and risks are finely balanced, the patient’s requests will usually be the deciding factor.

If, after discussion, the clinician still feels CPR would not be clinically appropriate he or she remains the right not to offer it. However the reasons should be explained to the patient and a second opinion offered.

There is still confusion between seeking consent for CPR and explaining about the choices and options for care that are available for a patient towards the end of life.

Failure to distinguish the purpose of a conversation in this way can sometimes result in burdensome and inappropriate conversations towards the end of life.

5.2: The right ‘not to know’

Some people may elect, as a valid expression of autonomy, to remain ignorant about the detail of their future death and what treatments or procedures may be administered.

Ideally clinicians will have discussed during advance care planning just how much a patient wishes to know about future treatment decisions – especially where a treatment is to be withheld.

Some patients do not want to discuss their future care or be involved in any future decisions about treatment.

The 2010 GMC guidance says: “If you (the clinician) conclude that the patient does not wish to know about or discuss a DNACPR decision, you should seek their agreement to share with those close to them, with carers and others, the information they may need to know in order to support the patient’s treatment and care.”

The same document outlines the steps doctors should take when a patient is unwilling to take part in decision-making about their treatment, including CPR.
Patients are entitled to leave their responsible clinician and healthcare team to act in their best interests but such a decision must be expressly made and the detail recorded in the patient’s notes.

Clinicians ought to have raised the subject with them to obtain that refusal to discuss.

This remains an area where clinicians must exercise considerable judgement and care – not just in reaching the decision but in confirming that the patient really does not wish to know about such a decision.

Detail should not be forced on the patient but raising the issue ensures the patient is able to place other decisions about their care or priorities in the proper context.

See further discussion of this in the advance care planning section.

The requirement to inform a capable patient or those close to a patient lacking capacity is the subject of a legal challenge as this web resource is being prepared.

5.3: Deciding against informing patients of a DNACPR decision to avoid an unnecessary burden

Clinicians must start from the position that patients with capacity are entitled to know when a DNACPR position has been made because it will not be successful.

The responsible clinician and clinical team must expect to communicate with the patient or representatives wherever possible and appropriate and keep a careful record of the conversations.

In the ‘vignettes’ section of this resource we outline how such a discussion might take place. It is better that the patient has the chance to discuss the issues and to refuse to participate in decisions, rather than not to be informed and for decisions to be made without their input.

If there has been no advance care planning or the patient refused to discuss the provision or withholding of certain treatments, clinicians will face challenges when the time comes to make a decision about CPR.

Whether there is a requirement to inform all capable patients – and those close to patients lacking capacity – is a sensitive and contentious issue with varying perspectives.

The requirement to inform a capable patient or those close to a patient lacking capacity is the subject of a legal challenge as this web resource is being prepared.

The 2010 GMC guidance says: “If a patient is at foreseeable risk of cardiac or respiratory arrest and you judge that CPR should not be attempted, because it will not be successful in restarting the patient’s heart and breathing and restoring circulation, you must consider carefully whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made.

“You should not make assumptions about a patient’s wishes, but should explore in a sensitive way how willing they might be to know about a DNACPR decision. While some patients may want to be told, others may find discussions about interventions that would not be clinically appropriate burdensome and of little or no value. You should not withhold information simply because conveying it is difficult or uncomfortable for you or the healthcare team.”
It continues: “If you (the clinician) conclude that the patient does not wish to know about or discuss a DNACPR decision, you should seek their agreement to share with those close to them, with carers and others, the information they may need to know in order to support the patient’s treatment and care.”

The 2007 Joint Statement also acknowledges that such conversations will not always be appropriate.

It says: “Careful consideration should be given as to whether or not to inform the patient of the decision. Although patients should be helped to understand the severity of their condition, whether they should be informed explicitly of a clinical decision not to attempt CPR will depend on the individual circumstances.

“In most cases a patient should be informed, but for some patients, for example those who know that they are approaching the end of their life, information about interventions that would not be clinically successful will be unnecessarily burdensome and of little or no value.”

However there is a strong legal view that this should only happen where the patient has made clear they do not wish to discuss a decision not to attempt CPR or in exceptional circumstances where sharing the information will cause the patient serious harm.

As noted above, the failure to inform the relatives of a person lacking capacity that clinicians had reached a DNACPR decision for a patient is the subject of a legal challenge as this resource is being prepared.

5.4: The traffic light approach to timing discussions

Every aspect of care planning is important and DNACPR decisions and their documentation form only part of this. The same attention should be given to all decision-making and it is the senior responsible clinician’s duty to ensure that his or her colleagues are aware of this and apply it to practice.

The traffic light diagram below summarises the key issues and priorities for consideration. The lights themselves represent speculative time windows ranging from years to days before death.

- On the left, arrows indicate the sequence of general clinical realities that the patient and the healthcare team face as the risk of dying begins to rise.
- On the right, are equivalent arrows that mark the parallel duties and obligations to communicate and plan with the person, and those close to them, that come with the escalating risk of dying.

The risk that a person will end up dying in a place or manner that they fear most or want least rises if this communication does not take place. It is reflected in the colour change from green to red.

The model reminds us that timely communication is a duty that exists at every stage of care. The earlier a matter is raised, the more time there is for reflection and for decisions to be checked.

(See explanation of acronyms below diagram)
Traffic light diagram acronyms:

EPaCCS: Electronic Palliative Care Co-ordination System
LPA: Lasting Power of Attorney (MCA 2005)
IMCA: Independent Mental Capacity Advocate (MCA 2005)
LCP: Liverpool Care Pathway for the Dying Patient

It is vital to recognise that:

- Decision-making processes and the patient’s right to express preferences apply to all clinical matters and not just CPR
- For clinicians to know what a person would want in an emergency or when they are temporarily or permanently incapacitated is a huge help and reassurance to everyone. It provides a clear and agreed framework within which to assess what might be in the person’s best interests.

In respect of end of life care generally, the earlier that patients and clinicians have the opportunity to discuss their respective views routinely and plan for future options, which may or may not include CPR, the better.

Open communication demystifies the dying process, empowers the patient and is at the heart of shared decision-making. Such discussions and advance care planning might be appropriate at the time of a specific diagnosis.

They might also be appropriate if the person’s health or quality of life is noticeably in general decline or there is likelihood that they may lose capacity.

This may enable the patient to make an ADRT while they still have capacity.
In other cases, the person might want to plan their future care while they are in good health. This might include the wish that they would rather die suddenly than receive CPR and face the uncertainty and risks that accompany it.

Again, this may enable a patient to make an ADRT, should they wish to do so.

Generally, poor practice in CPR decision-making involves combinations of poor communication and misunderstanding, failures in continuity of care and a remediable lack of education or competence. These failings are sometimes underpinned by a reluctance to engage in what can be sensitive and challenging conversations with very frail or elderly people with comorbidities.

Shared decision-making and care planning should be usual practice in all aspects of the care of all patients facing progressive, long term or multiple diseases. It is the preferred way to manage the uncertainty of advancing disease.

Contemporaneous, clear, accurate, legible records must include details on:

- Who was involved in discussions and decisions
- The clinical context in which discussions and decisions occurred
- The circumstances in which decisions (including decisions about CPR) may vary should the person suffer temporary or permanent incapacity
- The details of what was discussed.

There is a risk that end of life care policies could lead the senior responsible clinician to feel that clinical judgement is no longer necessary. Decisions could be delegated inappropriately to junior doctors without adequate support or supervision.

This may apply to care planning in general. This is an unacceptable delegation of their duty of care by a senior responsible clinician and indicates poor or cursory decision-making.

Local policies should be in place setting out who can make decisions relating to CPR. These should emphasise the continuing need for clinical judgement and the relevant competencies. The policies should meet the NCEPOD recommendation that CPR decisions for hospital patients should be made at or soon after admission by a senior clinician.

### 5.5 Advance care planning

Advance care planning (ACP) refers specifically to future circumstances when a patient no longer has the capacity to make an important decision. It includes:

- Decisions by a capable patient about immediate aspects of their care
- Decisions by a capable patient about their future care, in anticipation of possible future events. These decisions may be reversed or revised at any time by them if they have the requisite mental capacity
- Decisions by a capable patient about their future care in anticipation of future events, should they become incapacitated.

The MCA consolidated arrangements developed through Common Law specifying the process of making advance decisions to refuse treatment (ADRTs) and providing a precise definition of ACP. A new national document has helped clarify the meaning of many ACP-related terms.
ACP is a voluntary process of discussion and review involving individuals who have the capacity to anticipate how their condition may affect them in the future.

The outcome of that advance care planning only applies at a time when a patient is mentally incapable.

While a patient retains capacity, they have the right to refuse or accept treatment.

These discussions about their future care involve support and advice from health or social care professionals.

There is growing evidence of the benefits to patients of ACP, with a greater sense of control for patients; improving their chances of being cared for and dying in their preferred setting.

It is also linked to increased satisfaction with the quality of care in surveys of bereaved carers.

However, ACP discussions can cause distress and individuals, as has been discussed in relation to DNACPR conversations, must have the freedom not to engage in the process. A health or social care professional has to offer the patient the opportunity to engage in ACP in order for the refusal to be obtained. Any refusal must be clearly and fully documented.

Encouraging and enabling patients to express their current wishes is essential to effective communication.

It is also important because:

- Many people with an acute illness are temporarily compromised mentally and emotionally when urgent decisions are needed. Mental or other relevant incapacity is a common feature of progressive illness
- ACP sets on record choices or decisions about an individual’s care and treatment
- It provides information that can be shared, with consent, by those responsible for providing care or treatment if the patient loses capacity.

However only certain specific outcomes of ACP are binding.

A verbal or written advance statement of wishes and preferences, beliefs and values is simply evidence of what the patient’s wishes and preferences were when they had capacity. To be binding in decisions around life-sustaining treatment, it would have to be a written valid and applicable ADRT.

ACP could result in the appointment of a person with a Lasting Power of Attorney (LPA). This person has the legal power to make decisions on behalf of the patient if the power states this is the case. This can cover a patient’s property and financial affairs, or his or her personal welfare. This is also known as a Health and Welfare Legal Power of Attorney.

An LPA is obliged to act in the patient’s best interests. If the treating team disagrees with the attorney’s view, legal advice should be sought because the clinicians also have a duty to act in the patient’s best interests. This may require a court order to treat in the event of a refusal by an attorney.

As stated above, an ADRT is legally binding. Examples are available here.

Sections 24-26 of the MCA give individuals the legally binding freedom to refuse treatments in advance in specific circumstances. An ADRT need only be written when refusing life-prolonging treatments.
Only a written, witnessed ADRT which states that it is to apply even if the patient's life will be at risk is valid in relation to CPR.

Any ADRT must be written with care. It is only legally binding if it is valid – that is it was written when the person was over 18, informed and capable. There must be no coercion involved.

Clearly, the ADRT would not be valid if the patient had withdrawn it or done anything else to suggest they no longer wished it to apply. It must be applicable (ie its scope covers the present situation and proposed actions and treatment).

The legislation does not specify a format for an ADRT.

While the absence of a single, recognised ADRT form empowers patients, it can make it more difficult for healthcare staff to recognise or accept such documents.

See the documentation section for further discussion on these issues.

The 2010 GMC guidance, aimed obviously at doctors, says: “Some patients may not be ready to think about their future care or may find the prospect of doing so too distressing. However, no-one else can make a decision on behalf of an adult who has capacity.

“If a patient asks you to make decisions on their behalf or wants to leave decisions to a relative, partner or friend, you should explain that it is important they understand the options open to them and what the treatment will involve. If they do not want this information you should try to find out why.

“If the patient still does not want to know in detail about their condition or the treatment, you should respect their wishes as far as possible. But you must explain the importance of providing at least the basic information they need in order to give valid consent to a proposed investigation or treatment. This is likely to include what the investigation or treatment aims to achieve and what it will involve…"

“If the patient insists that they do not want even this basic information, you must explain the potential consequences of carrying out an investigation or treatment if their consent may be open to subsequent legal challenge. You must record the fact that the patient has declined relevant information and who they asked to make the decision about treatment.”
6. Outcomes of CPR

6.1: Defining successful resuscitation

Ambiguity about what we mean by successful resuscitation complicates the clinical or personal decision-making process.

For many patients, the most that can be achieved is to return someone to the state they were in before their arrest. Obviously, if the person was otherwise fit and well at that point, then this would be a considerable success.

In some cases, for example, where someone arrests while awaiting cardiac surgery, CPR may allow them to have their operation and achieve a better state of health and quality of life.

However, in other cases a person’s life is saved but the individual is in a condition he or she might consider intolerable. This could include having new or more severe health problems as a result of the arrest and resuscitation.

There has been little research into the quality of life in people with progressive illnesses who have survived CPR.

A commentary in 2011 (Ref 14) emphasised the loss of independence after CPR: “Of these survivors (of successful CPR), 86% had been admitted to hospital from home but only 51% were well enough to return there.

“So, despite the noble goals, CPR can perhaps be regarded as a medical intervention that carries significant risks to the future wellbeing of the patient.”

This illustrates that, depending on one's perspective, CPR can deliver real benefit to patients (after all, just over half of the patients were eventually well enough to return home).

However, clinicians’ duties require them to consider the impact on the other 49%. Some of these patients will be more dependent than they were previously.

6.2: What the data shows for outcomes

As noted elsewhere in this resource, the likelihood of any single attempt at CPR being successful in terms of re-starting the heart or restoring breathing depends on a variety of factors.

One large study of hospital patients identified the highest survival rate (37% survival to hospital discharge) in patients who had a ventricular fibrillation (VF) cardiac arrest (Ref 15).

As the NCEPOD 2012 report pointed out, most cardiac arrests amongst hospital patients occur in general ward areas and are often unmonitored. Amongst this group the chance of survival to discharge is significantly lower.

Approximately 53% of deaths take place in our hospitals. CPR is attempted in approximately 19% of these hospital deaths.

The success of CPR varies widely depending on:

- The situation where arrest has occurred
- The time from CA to starting CPR
- The time between the CA and defibrillation of a shockable rhythm
The cause of the arrest
- The presence of co-morbidities
- Access to ventilation/ITU and other appropriate care following the return of spontaneous circulation.

As the figures provided below indicate, we can identify groups of patients with very different prospects for immediate and long-term survival following CPR.

CPR can be successful for up to 61% of patients who:
- Were aged under 70 years
- Had an arrest that was witnessed
- Had ventricular fibrillation as the initial rhythm disturbance. (Refs 16-21)

Some 47% of patients in this group who survive CPR are discharged home.

More than half (54%) of those people discharged home are still alive three years later. This group has the highest likelihood of survival.

 Patients who have a cardiac arrest due to a non-shockable rhythm have:
- A 20% immediate survival rate
- A rate of discharge home below 10%
- A five-year survival rate below 3%. (Refs 22-23)

Survival in non-monitored hospital environments is low (about 15% survival to discharge) compared to that for equivalent patients who receive interventions within a minute (Ref 24).

When CPR is used following an arrest during ambulance transport:
- There is a 31% chance of restoring circulation
- Less than 20% of these patients (6% of all such arrests) have a favourable long-term outcome (Ref 25).

In witnessed, out-of-hospital arrests where CPR is used:
- Spontaneous circulation is restored in nearly 40% of cases
- 16% survive to discharge
- 12% survive 6 months (Refs 26-28).

For some groups of patients or in some circumstances, attempting CPR produces very low survival rates, for example when:
- Amongst people who have a non-witnessed arrest outside hospital, fewer than 1% survive 30 days
- Patients with an irreversible life-threatening illness, and where death is anticipated in the near future, attempted CPR offers no realistic prospect of immediate survival
- People who have advanced end-stage cancer have less than 1% chance of return of spontaneous circulation after CPR. Survival to discharge is close to zero (Refs 29-31).
7. Documentation

7.1: The DNACPR decision form

The senior responsible clinician must ensure that a form recording a DNACPR decision is completed in a clear and precise style. It should ensure that all healthcare professionals involved in an individual’s care are aware of the decision that an attempt at CPR would not work or would no longer be in the patient’s best interests.

The form is intended to be a clear, accessible and recognisable statement to help professionals reach an immediate decision when an arrest occurs.

The DNACPR form specifically refers to heart and lung resuscitation. It does not in any way limit the provision of other forms of treatment from which a person may benefit. It is designed to prevent specific inappropriate treatment and actions, not to stop beneficial interventions other than CPR.

DNACPR decisions should be reviewed frequently when caring for those with progressing and terminal diseases as each person’s wishes are individual and may change frequently. It can also be suspended or cancelled as circumstances change. For example, a DNACPR decision will often be suspended during surgery.

The DNACPR form represents a considered opinion that has been discussed by the clinical team as a whole. In many cases it will record the wish of a patient (or those close to them) that CPR should not be attempted.

7.2: Shared documentation to improve care co-ordination and transfers

Even within the same geographical area, organisations involved in caring for those at the end of life can have polices and documentation that differ both in appearance and emphasis. Only some of these differences reflect justifiable, particular institutional needs.

Ambulance crews are particularly vulnerable to being unclear as to whether a DNACPR decision from the sending organisation remains applicable or valid in transit or when the patient arrives at their destination.

This risk is accentuated if the sending and receiving organisations and the ambulance service have widely-differing documentation.

The two most significant risks are:

- Inappropriate CPR during or soon after transfer
- That a death may be viewed as unexpected and be subject to inappropriate involvement of the police or coroner if the person dies during or soon after transfer (see Expected deaths outside hospital).

While there are excellent examples of shared local and regional policies and agreements, they are still not the norm.

The 2007 Joint Statement says on pages 19-20:

“Any decisions about CPR should be communicated between health professionals whenever a patient is transferred between establishments.”
“In the past, problems have arisen with such transfers because CPR decisions have not been communicated or have not been accepted as valid by the ambulance service or the receiving organisation.

“There are many examples, at local and regional level, of ways of ensuring that decisions are disseminated to all those involved in the care of patients. For example, agreeing standard resuscitation forms that are recognised locally or regionally by all healthcare establishments, the police, out-of-hours service providers and the ambulance service. These forms may be transferred with the patient, copied to relevant people, or held in an agreed central location.”

However, whatever the local circumstances, there are some minimum requirements. These include:

- Clinical documentation that should be both transferrable and immediately recognisable by different clinical teams and valid across healthcare organisations.
- Procedures to ensure continuity of care must be clear and explicit for the hand-over of decision-making responsibility between clinicians when a patient moves between teams or settings. (A sample transfer policy addendum is available [here](#)).
- Such procedures should include an agreed notification process with the police and coroner that avoids their unnecessary involvement when an expected death occurs during transfer or at home soon after a transfer (Examples are available [here](#)).
- Transfer policies should incorporate a section on the status of the CPR decision by the senior responsible clinician from the sending organisation.

CPR decisions should be recorded routinely as part of clinical record-keeping. Appropriate pro-forma documents would help ensure consistency and clarity. This could reassure patients that their wishes are clearly recorded and will be respected should they become incapable.

Examples of formal care planning and treatment decisions documents such as advance statements, treatment escalation or emergency care plans, advance decisions to refuse treatment and DNACPR forms can be found in links from the resources page.

The core content for the national information standard for End of life Care Co-ordination (ISB 1580) supports the recording and communication of people’s end of life care choices and preferences (Ref 32).

It includes a data item for recording whether or not cardiopulmonary resuscitation should be attempted.

The data item includes three codes:

1. For attempted cardiopulmonary resuscitation
2. Not for attempted cardiopulmonary resuscitation
3. (Person) not aware of do not attempt cardiopulmonary resuscitation clinical decision.

Complying with the standard could help ensure that all healthcare professionals involved in an individual’s care are aware of the patient’s CPR status.

The record-keeping guidance that accompanies the standard supports health and professional care professionals using EPaCCS or other coordination systems.
It includes guidance on advance decision documentation in section 6.7 of the guidance.

The Resuscitation Council has also developed separate model DNACPR forms for use in cases involving adults and children. The forms, together with guidance notes for completing them, are available here.

As well as applying to NHS health organisations, this uniformity of approach and support should extend to social care, hospices, care homes and independent hospitals. It would also provide clarity to coronial and police authorities.

A consistent understanding, agreement and approach amongst this range of organisations and professionals can lead to:

- A reduction in the number of inappropriate CPR attempts
- A reduction in the risk of clinically inappropriate DNACPR decisions being made or applied
- An improvement in the communication of decisions amongst staff and between staff, patients and those close to them
- Greater co-ordination, use and recognition of uniform documentation to limit unnecessary intrusion by attending professionals at the time of an expected and natural death
- An opportunity for ambulance services to support patients as they die without being obliged to attempt resuscitation or transfer to a hospital emergency department
- A consistent response from all sectors when a patient with a DNACPR form dies in transit; one that maintains dignity and spares relatives unnecessary distress
- A rise in a patient outcome measure such as a sense of dignity and family satisfaction.

7.3: Potential risks with documentation

A form which gives only a single (yes or no) DNACPR recommendation presents problems when a patient’s clinical situation may be more complex. CPR might be appropriate in one circumstance and not in another.

For example, patients with neuro-disability are vulnerable both to reversible/transient respiratory arrests and to irreversible CA when they die. Other patients may develop respiratory problems during the introduction of drugs such as anaesthetic agents during surgery.

Over time, the broader influence of the MCA and shared decision-making approaches should improve collaboration. However this will require commitment on behalf of professionals and organisations involved in end of life care and should be addressed in training and education.

Although CPR decisions will continue to be recorded separately, this trend should make them a routine part of broader individual planning tools and documents that reflect the patient’s involvement and other preferences.

This should be encouraged actively as good practice. Careful consideration should therefore be given in the future to developing and adapting DNACPR and emergency healthcare plans.
as a way of embedding CPR decision-making in overall emergency care planning and improving end of life care in general.

We outline below problems that can arise concerning documentation.

7.3.1: Mistaking a DNACPR form for an ADRT

An ADRT signed by the patient and witnessed, stating that it is to apply even if the patient’s life could be at risk, is a legally-binding document refusing treatment if validly made and applicable to the current circumstances.

A DNACPR form represents an opinion and recommendation about a specific patient by the responsible clinician or team.

Whilst authoritative, occasionally circumstances might arise where an attending clinician would rightly consider over-riding a DNACPR decision.

However if the decision appears to set out a clear indication of the patient’s wishes even though it is not a formal ADRT, those wishes should be respected taken into account in a best interests decision is being made when the patient is unconscious.

If the individual is at home or in a care or residential facility, the DNACPR form provides clear guidance to any professional responding to a clinical crisis that any treatment short of CPR may be appropriate. If the heart and lungs have stopped, however, the person has died and CPR would be inappropriate.

7.3.2: Avoiding or withholding CPR inappropriately

There is an important and proper default in healthcare in favour of CPR. Hence, the primary purpose of DNACPR policies is to reduce inappropriate or unwanted attempts at resuscitation.

The attending clinician must make a reasonable effort to check if clinical circumstances or a patient’s preferences have changed and make a reasonable decision based on their current assessment.

This applies also to those situations where the patient has an ADRT in place in order to determine whether it was validly made and is applicable to the current circumstances.

7.3.3: Clinicians interpreting a DNACPR decision to mean “do not assess”

A DNACPR decision is a considered, authoritative opinion, but not a binding instruction, unless it is being used to record the presence of a valid and applicable ADRT or the clearly expressed wishes of the patient in the absence of a formal ADRT.

Clinical assessment and judgement based on the immediate circumstances of the arrest is still essential. For example, an acute airway obstruction with food is a very different clinical situation from a heart that has stopped because someone has died.
Hence, a patient may have agreed a DNACPR decision because they have progressive heart disease but would not object to a resuscitation attempt if respiratory arrest was triggered by choking.

7.3.4: Rigid forms leading to inflexible thinking by staff

Single decision forms that provide a straight ‘yes or no’ decision in relation to DNACPR can be straightforward and simple. They are common but can present challenges if clinicians are not properly trained or appropriate processes are not in place.

The wording of the forms should make clear that decisions must be reviewed with appropriate frequency and this should be reinforced by local policies and training.

Rigid dates lack the flexibility to respond to the individual patient, any changes in their clinical condition and/or available treatments. This approach also makes administrative error more likely and creates uncertainty over whether, for example, CPR should be started in a dying patient when it appears the DNACPR form has ‘expired’.

Circumstance-specific forms are arguably preferable as they state clearly the circumstances in which the CPR decision should be followed.

Nevertheless, they must be patient-specific and can cross boundaries, but are considered by some to be too complex in an emergency. This is an area in need of debate and research.

7.3.5: Basic forms may not satisfy the needs of complex patients

In some complex patients with neurological disabilities or young people with complex long-term but life-limiting conditions, decisions for CPR and DNACPR decisions may coexist. This requires decisions at the time based on assessment of the immediate clinical circumstances.

Combined approaches that also use emergency management plans or treatment escalation plans alongside specific DNACPR forms may be helpful in such situations. Some regional policies commendably take this approach already.
8. Official and regulatory protection for patients

8.1: Professional and organisational responsibilities

When a person accesses any health services, s/he has a right to care that is competent and safe. This is the duty of care that is ensured through clinical governance.

Every healthcare professional also has an individual duty of care through their professional body and its code of conduct. The four bodies that are most relevant to CPR are the General Medical Council, the Nursing and Midwifery Council, the Health and Care Professions Council and the National Association of Emergency Medical Technicians, which has a code of conduct for paramedics.

This offers a double layer of protection for the public: the duties of each clinical professional and the governance structures of their employing healthcare organisation.

GPs have a variety of arrangements depending on their partnership or private practice structure or if they are directly employed by an organisation. They are nevertheless all covered by the GMC code.

8.2: Professional duties in CPR decision-making

The same fundamental duties apply to CPR as any other decision.

Where CPR may be successful, health professionals must discuss and assess with patients, wherever possible, the balances between risks, the benefit and any burden of attempting CPR in their particular circumstances.

For further discussion of these issues see here.

Where CPR will not be successful, health professionals should consider the individual circumstances of the patient and decide whether it is appropriate to communicate the DNACPR decision to them (or those close to the patient if they lack capacity).

However clinicians should inform the patient of a DNACPR decision except in the most exceptional circumstances.

If there is a clearly justifiable reason not to inform the patient, that reason should be recorded, for example if a patient is nearing a natural death and the patient has indicated they do not wish to be informed of such decisions. For further discussion of this issue see here.

The requirement to inform a capable patient or those close to a patient lacking capacity is the subject of a legal challenge as this web resource is being prepared.

Where CPR may be successful and the patient lacks capacity, health professionals must:

- Respect a valid and applicable advance decision to refuse CPR if this exists in the form of an ADRT
- Discuss treatment with the patient’s attorney (if the patient has made a health and welfare LPA) or court-appointed deputy (if one has been appointed) as appropriate or
- In the absence of an ADRT, attorney or court-appointed deputy, discuss the patient’s likely wishes and preferences with relatives or friends of the patient and
• Act in the patient’s best interests, as defined in the MCA, taking into account their previously-expressed wishes and the information above.

In the absence of anyone other than a paid carer being able to provide insight into the patient’s views and wishes the health professionals must seek the view of an IMCA, if time permits, to inform the decision-making process. CPR amounts to serious medical treatment as defined by the MCA.

This is neither required nor practical in an emergency but again underlines the need for advance care planning wherever possible in order that clinicians can act in the patient’s best interests.

Where there is disagreement about a decision not to attempt CPR because it will not be successful, a second opinion should be offered wherever possible.

The 2007 Joint Statement is clear about this with regard to patients with capacity, those close to them and to those acting on behalf of a patient who lacks capacity.

With regard to the latter group it says: “If the patient lacks capacity and has appointed a welfare attorney…or if the court has appointed a deputy or guardian with similar authority to act on the individual’s behalf, this person should be informed of the decision and the reason for it.”

If the explanation is not accepted or there is any disagreement over the decision, a second opinion should be offered.

When clinicians do not believe that CPR will be successful for patients with capacity, a second opinion should be offered if there is disagreement over the decision.

The 2007 Joint Statement says: “Similarly, if those close to the patient do not accept a DNAR decision in these circumstances, despite careful explanation for its basis, a second opinion should be offered.”

Occasionally a doctor feels unable to comply with a patient’s wish for CPR to be attempted if necessary because he or she genuinely feels the harm will outweigh the benefit. On other occasions members of a clinical team may disagree about what is in the patient’s best interests.

“In (these) unusual circumstances”, the 2007 Joint Statement says “…seeking a second opinion is recommended so that patients may be given an opportunity to review their decision in the light of further advice”.

Clinical training and education should be available to help clinicians understand how:

• The concept of health and the balance of medical benefits and risks change when treatments move increasingly to prioritise quality towards the end of life
• This applies to care planning and an understanding of best interests
• This affects the responsibility of the senior responsible clinician in decision-making.

Clinicians also need to be trained in assessment of the risks and benefits of CPR in the range of clinical situations they are likely to encounter.

Communication training is also important to ensure that clinicians are competent to undertake sensitive discussions with patients and those close to them.
9. Changing perspectives: what health, dignity, burdens, risks and harms mean for the dying person

9.1: Concepts that can help in reaching CPR decisions

These are amongst the two basic pairs of concepts that people use in deciding what may be in their best interests. These concepts may change in importance or relevance to that person - and therefore change their attitude to CPR - as they approach the end of their lives.

The concepts are:

- Health and dignity
- Benefits and potential risk of burdens, and harms.

We need to understand them theoretically to help patients apply them practically to decisions about treatments generally, and CPR in particular.

Clinical interventions are primarily about benefit.

Promoting or maintaining health is therefore a judgement with a patient and colleagues of the balance between benefit and harms. The GMC’s professional code summarises this as ‘overall benefit’.

This allows clinicians the flexibility to ensure that the assessment of overall benefit is contemporaneous and takes account of factors that are not directly medical. These include the patient’s own priorities.

Language describing the negative aspects of treatment can present difficulties.

Terms such as ‘burden’, ‘harm’ and ‘risk’ are subjective and are shaped by the values of the person using them. They can cause confusion by being open to misinterpretation or meaning different things to different people.

However, reaching a judgement of what is in a person’s best interests requires discussion of these issues. Section 4 of the MCA 2005 gives the legal framework for formulating best interest decisions. This is covered here.

In progressive disease it is often difficult to distinguish the impact of disease progression from that of the effect of a treatment. For example, the effect of chemotherapy on energy levels may be ascribed to the drug when in fact it is due to the cancer. Altered consciousness or drowsiness can be blamed on analgesic drugs when the patient is actually beginning to die.

Finally, risk and the individual’s judgement of what is acceptable is individual personal, contemporary and subject to a variety of complex factors. The patient is likely to find that burdens and harms which they once accepted, are less acceptable or even unacceptable as their disease progresses.

As CPR may involve a risk of prolonged intensive care, total dependency or minimal consciousness, a person who is nearing the end of their life may consider that risk unacceptable. By contrast, those with no immediate likelihood of unavoidable death may choose to accept that risk.

The MCA and professional codes, such as the GMC’s Consent: patients and doctors making decisions together, emphasise that assessing a person’s best interests means far more than just considerations of whether a treatment will work (Ref 33).
9.2: The risk, burdens and harms of CPR

Following a CA, immediate action is needed to ensure that CPR delivers the maximum possible benefit at lowest possible risk. Death is inevitable if CPR is not attempted.

CPR carries a level of risk and severity of burdens and harms that in any other treatment, such as surgery, would demand discussion and informed consent to treat.

These risks include:

- Broken bones and organ damage
- Injuries that will occasionally be fatal for patients whose heart is re-started or breathing restored
- A life of neurological deficit or minimal consciousness.

9.3: Balancing risk, harms and burdens against the benefit of CPR

While these risks are significant and real, the balance against the potential benefit clearly depends on individual circumstances.

For example, the discussion with a 45-year old patient who is otherwise well until admitted with acute myocardial infarction would highlight the potential benefit of CPR. There would be a good chance of successful resuscitation against a relatively low risk of harm.

There is an argument that the risks, burdens and potential harms should mean that all patients with a significant risk of needing CPR, where it could be successful, should have the opportunity to consent or refuse it in advance.

This is reflected in guidance and statements from a number of national bodies and it accords with the principles of the MCA.

The MCA states that a patient should not be seen as unable to make a decision unless all practicable steps to help them do so are exhausted.

The Act’s Code of Practice says that the legislation will ensure that patients will “participate as much as possible in any decision made on their behalf.”

The 2007 Joint Statement by the Resuscitation Council, BMA and RCN (p10) confirms this: “If CPR may be successful in re-starting the patient's heart and maintaining breathing for a sustained period, the benefits of prolonging life must be weighed against the potential burdens to the patient.

“This is not solely a clinical decision and must involve consideration of the patient’s broader best interests including their known or likely wishes. In these circumstances, discussion with the patient (or, if the patient lacks capacity, those close to the patient) about whether CPR should be attempted is an essential part of the decision-making process.”

9.4: Best interests

The decision whether or not to attempt CPR involves far more than the factual matter of probabilities of success. It must take account of what the person wants or what he or she considers to be in their future best interests.
A consideration of best interests must include not only clinical issues, but also the advantages and disadvantages of the options in relation to the patient's welfare, family life and social, recreational and daily living activities.

It should also take into account the patient's religious or spiritual beliefs and views which may be relevant and significant to the patient.

How a patient in these situations decides whether CPR is in their best interests is unique to them.

A patient with capacity has the right to make a decision that appears irrational or eccentric. Indeed, such a decision, if made with capacity, will be binding if it is recorded as an ADRT.

9.5: The changing balance as health deteriorates

Health is generally defined in physical terms but the World Health Organisation (WHO) uses a broader definition: “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”

Similarly, dying is not just a medical event - it is a social process: people die from a life as well as a disease or physical event.

As people age, become frail or their disease “journey” progresses, the components of their global health will change in a way unique to them.

However, one thing is certain: as treatments become ineffective or when there is nothing effective left to limit a condition, treatment that once provided benefit may become burdensome, excessively risky or cause harm.

Since no treatment is without some burden, when it is no longer therapeutically effective, all that remain are the burdens.

At this point, patients may change their priorities. They might move from wanting good physical health to a more holistic or less “medical” requirement to be free of symptoms. Other things such as familiar surroundings, time with friends and family and setting their affairs in order will rise up their list of priorities.

In this way, many people who face death in the near future may begin to see themselves as “healthy” from a sense of social, mental and spiritual well-being in spite of being physically disabled, dependent or even bed-bound or in the process of dying.

This is directly relevant to CPR because a dying person’s views about CPR are likely to change as they begin to accept death as natural and something that no longer must be staved off at any cost.

Non-physical factors tend to become more important in a person’s view of their health and best interests

The treatments they want, accept or refuse may reflect this.

9.6: Dignity and health

Opportunities to address new priorities are essential if people approaching the end of life are to find meaning, and to be “healthy within their disease”.

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However, that requires time that should not be wasted on medically pointless treatments when the objective for a person is to conclude their life well, not just to live longer.

This also requires that patients are informed of the options that are open to them and those that are not—except in the circumstances outlined in the 2007 Joint Statement. Knowing that a DNACPR decision is clinically indicated will normally be of paramount importance to a patient.

There are of course exceptional situations where the potential personal benefit from a treatment with questionable benefit may outweigh the burden. For example, an intervention may allow the individual a chance to be present for a significant family event, such as a wedding or the birth of a child or grandchild.

The treatment, although intrusive and painful, may produce a direct social and welfare benefit by prolonging life for a short period.

**Shared decision-making** and **advance care planning** at an early stage allow a patient to consider decisions about treatment escalation, including CPR, in advance. They will not be burdened with the consequences of earlier indecision when their thoughts and efforts at the end of life would be better focussed elsewhere.

Of course, in some cases patients revisit their earlier decisions.
10. The challenges posed by the complexity of modern healthcare

10.1: The need for effective team working

Modern clinical care can be so complex and specialised that often a person is receiving care from several medical teams at the same time.

Treatments are frequently complex and patients often have several comorbidities.

This can lead to problems, especially when it comes to broader decisions about that person’s whole care, what they may wish for and the limits of treatments that they are willing to accept in the future.

Additionally, decisions about treatments will usually involve conversations about potentially life-saving interventions, overall benefit and overall harm. There is a risk such discussions with patients may not take place due to lack of clarity over which team has the ultimate responsibility for engaging with patients on these issues.

Many specialists feel anxious, uncomfortable or insufficiently skilled for conversations about uncertainty and the end of life.

This could be addressed by developing a framework for establishing competence in all practitioners likely to be responsible for communications about care planning – including CPR decisions – when a person is under the care of more than one team.

This would require training in assessing the risks and benefits of CPR for individual patients as well as the communications skills needed for sensitive discussions.

In complex cases involving several teams there should be clarity about which team is leading the care, with a named senior responsible clinician within that team responsible for taking decisions.

This person need not necessarily be a doctor. However they must be sufficiently knowledgeable to deal with the questions and issues that the patient may want to discuss.

Training materials and information sources can be found here.

The rise of multi-disciplinary teams (MDTs) has also helped reduce the risk of poor care through lack of co-ordination and communication.

MDTs can take a number of forms; while some are constituted formally others may be “virtual”.

MDT-working makes it less likely that a team will focus purely on the diagnostics and technicalities of medical care.

Different clinical disciplines will focus on different aspects of the person. Bringing these disciplines together in an MDT ensures these different aspects of a person are considered together. The MDT is an increasingly common and effective feature of the health and social care landscape.

10.2: Re-emphasising the role of the senior responsible clinician

The healthcare team is obliged to share decision-making with the patient except in the circumstances outlined in the 2007 Joint Statement. These have been outlined previously and involve placing an inappropriate burden on someone nearing the end of life.
It is also clear that the senior responsible clinician must be identified and known to the patient and those close to the patient.

However, it should be remembered that complex decision-making is best undertaken by MDTs, or by clinicians working in a multi-professional environment. Advance or emergency care planning which includes a DNACPR recommendation is an example of such decision-making.

While the senior responsible clinician, or their delegate, is obliged to make appropriate CPR decisions or recommendations for those under their care, this is best done as part of a team. However, decisions to spare people CPR should not be delayed simply to go through the motions of team consultation.

It may be that non-medical clinicians, with their broader view, are sometimes best placed to discuss CPR decisions - either under their own or delegated authority.

The RCN would welcome the expansion of the role of ‘senior responsible clinician’ to include nurses with the necessary skills and competence. It sees no legal reason why a nurse should not fulfil this role.

Nurses are often best-placed to have discussions with people about their CPR decisions as part of the wider context of preferred priorities of care. This can apply particularly to nurses working in care homes and specialist palliative care settings and certain specialist practitioners, such as heart failure nurses.

However, the RCN believes there is a need for clear guidance on the skills required and acceptance of the nurse as the appropriate lead clinician on the part of the NMC. Until then, the RCN says, any nurse undertaking this role should only do so under the delegated responsibility of the lead clinician and within local policy guidelines.

10.3: Discussions between the senior responsible clinician and the patient

An effective discussion between the patient and any senior responsible clinician would be one that:

- Preserved the default in favour of CPR (where that is considered appropriate)
- Opens the opportunity for someone to consent to or refuse CPR if an arrest is a real possibility while not forcing the individual into an unwanted conversation
- Makes it the norm to discuss the realities and risks of life around death and dying.

Good communication skills and confidence are central to such a discussion and should be part of everyone’s continued professional development (see resources).

With reference to ACP and CPR advice or decisions, the identifiable senior responsible clinician should be someone who knows the person’s immediate problems, their clinical history, their current capacity to be involved in decisions and their best interests.

While this detailed knowledge will be known across the team, it may not be known directly to the senior clinician who takes ultimate responsibility. DNACPR forms reflect this by having space for a countersignature.
10.4: Identifying the senior responsible clinician

At first sight identifying the senior responsible clinician in a patient’s care seems straightforward.

However, it is complicated by the many settings for healthcare and the varying nature and configuration of teams. There are different and distinct approaches to this issue depending on whether the individual is cared for in the community or in an acute setting.

There should be flexibility in identifying the senior responsible clinician.

In most instances, discussions or decisions about CPR would be undertaken by senior members of the primary care team. However this should not preclude specialist doctors and nurses in another setting who know the patient discussing it with them and those close to them.

Whether this happens in an outpatient clinic or following admission to hospital or hospice, it is crucial that there is prompt and detailed communication with the GP and the primary care team about the content and outcome of these discussions.

The patient’s CPR status will be one of the key decisions around care of the patient and it is therefore the responsibility of the clinician in charge of his or her care.

The senior responsible clinician is likely to change when the individual is transferred between:

- Teams within an institution
- Hospital, hospice or other care facility and home, in either direction
- Two healthcare facilities.

Readers should therefore also see the discussion about different organisational approaches and the Reflections section of this recourse.

Some healthcare communities and some regions have developed very good cross-organisational policies that are clear about how long a senior responsible clinician’s recommendation applies once the patient moves to another team or organisation or to their own home.

Transfer policies should outline the status of the sending senior responsible clinician’s CPR opinion pending the patient’s next clinical assessment. They should be explicit, clear and unambiguous about how the senior responsible clinician is identified.

In relation specifically to DNACPR recommendations and forms, the handover to the next senior responsible clinician must involve clear communication around key issues.

These include whether a person’s circumstances have changed or are likely to change when they move. The documentation should also state the urgency for - and extent of - a fresh clinical assessment when the person has transferred.

10.5: The senior responsible clinician in the community

If the GP sees the patient regularly and engages in ACP with the patient, then it will often be appropriate that s/he remains the senior responsible clinician unless the patient is admitted to hospital.
However, GP input into the patient’s care may only be necessary periodically and the GP may not be the health professional who has the latest and most pertinent information about the patient’s condition and preferences.

Frequently the patient will see senior and experienced nurses much more frequently than they see their GP.

In these situations, some specialist nurses (for example those working in palliative care settings or heart failure nurses), care home nurses and community matrons may be best placed to assess and assist patients with decision-making – including CPR decisions.

As noted above, there is no legal reason why a nurse should not fulfil the role of senior responsible clinician.

There are specific competencies and training in communication and the decision-making process for nurses who are given decision-making authority in relation to CPR.

The RCN has previously asked for further guidance on the skills required and explicit recognition that some nurses could appropriately fulfil the role. It has cautioned that until those conditions are met, any nurse undertaking this role should only do so under the delegated responsibility of the lead clinician and within local policy guidance.

However the 2007 Joint Statement said that it is not mandatory that a nurse requires delegated responsibility.

When the statement was published in 2007, the potential role of the nurse in leading CPR decision-making was one of several areas misinterpreted by the media.

The Resuscitation Council issued a clarification statement (Ref) emphasising that the increasingly multi-disciplinary nature of healthcare and the developing status of nursing meant nurses are sometimes the most senior clinician in charge of a patient’s care.

Responsibility for CPR decision-making “must always rest with the most senior clinician in charge of a patient’s care”, the clarification continued.

It added: “In the majority of cases this will be a registered medical practitioner but in some situations, such as in nurse-led palliative care services, a senior nurse with appropriate training may fulfil this role, subject to local discussion and agreement.”

The clarification emphasised that the 2007 Joint Statement stressed the importance of both shared decision-making involving the patient and other members of the clinical team.

A medical consultant seeing the patient at an outpatient clinic could also be appropriately placed in some cases to fulfil the role of senior responsible clinician.

This consultant is responsible for the advice or treatments given and for which the GP made the referral.

Often an outpatients’ clinic is the best setting to reach a DNACPR decision. In some cases the first conversation about CPR will be initiated by the consultant in his or her outpatient clinic. In other cases, the patient has discussed the issue with their GP or another senior primary care professional but sought to discuss it further with their consultant.

There are anecdotal reports that patients sometimes agree a DNACPR decision with their GP but wish to discuss and confirm it with their consultant out of concern that they might be “letting the consultant” down by being seen to “give up” on the consultant’s treatment.
As stated elsewhere, any DNACPR decision reached in outpatients must be communicated to all relevant professionals and organisations.

While, the person’s GP usually retains overall responsibility for the healthcare of someone seen in an outpatients’ clinic, there is nothing to prevent the consultant being identified as the senior responsible clinician in such circumstances.

10.6: The senior responsible clinician for patients in hospital

If the patient is admitted to hospital, the senior responsible clinician is initially, by default, the first consultant involved in providing care to the patient.

However should the patient move between teams, local governance mechanisms must be in place to ensure that the senior responsible clinician is both identified and appropriate.

In the reality of the modern acute hospital this could initially mean the emergency department physician. However it is likely that lead responsibility for a patient admitted to hospital will, following triage, swiftly transfer to a specialist consultant on a ward or in ITU.

Most hospital teams are led by a consultant doctor. Patients may be under the care of several clinicians at different times or simultaneously and some consultants work in specialist teams.

There may be no clear equivalent of the GP in the community fulfilling an unambiguous, overall, default role as senior responsible clinician.

This is not surprising given the extent of specialisation and the rise of highly specific technical knowledge and expertise.

However, it may compromise the ability to offer holistic care. It can also mean no-one takes an overall view of - and overall responsibility for - the patient.

Specialists point out that they are best advising over matters in which they have expertise and on which they should remain focussed. However they are also professionals with strong values and a desire to do the right thing.

Therefore they should accept that having the skill to undertake difficult conversations is core to being a good doctor, irrespective of their degree of specialisation.

The NCEPOD study on CPR in hospitals produced important recommendations on early consultant involvement.

The study said: “When during the initial admission CPR is considered as inappropriate, consultant involvement must occur at that time.”

It continued: “Where patients continue to deteriorate after non-consultant review there should be escalation of patient care to a more senior doctor. If this is not done, the reasons for non-escalation must be documented clearly in the case notes.”

The above would suggest that where more than one consultant-led team is involved in a patient’s care, one consultant should be designated as senior responsible clinician.

The specialist filling this role could change in response to the patient’s condition and needs. This would mean that the responsibilities for global decisions such as CPR transfer between teams or across settings as the patient moves or their condition changes.
Except in the most integrated and innovative services, consultants seldom recognise the role the GP could play in a virtual team spanning primary and secondary care.

Yet the GP is often the professional with the greatest knowledge of the patient and their wishes.

The move towards greater integration between primary and secondary care and the adoption of explicit equality in interdisciplinary practice opens up other possibilities.

For example:

- Some senior nurses have particular skills in holistic assessment beyond the detailed elements of a patient’s pathologies and they could be given this authority in what may be seen as medically-led teams
- In some situations it may be appropriate for GPs to consider extending their senior responsible clinician role in ACP or DNACPR decision-making into some of their patients' hospital inpatient episodes in close liaison with the hospital healthcare team
- Whenever possible, GPs should be consulted in difficult or complex situations to provide seamless high-quality care that is not impeded by artificial organisational boundaries and poor communication.
11. Reflections

CPR policies and documentation

1. The professional bodies, in collaboration with the Resuscitation Council, should consider developing recognisable documentation for CPR and related decisions. This could include, for example, emergency healthcare plans that are transferrable as patients move between settings and services. Clinicians and patients would be reassured if there were certain common features of documentation. This work can build on existing regional documentation and the 2007 Joint Statement.

2. Generally, circumstance-specific forms - such as emergency healthcare plans - may be preferable as additions to a distinct DNACPR form. These plans can state the circumstances in which the CPR decisions may vary.

3. A standard advance decision to refuse treatment (ADRT) form could usefully be made available to the public and adopted by organisations. This will reassure clinicians as to a document’s authenticity and validity; and increase recognition - making it more likely that a patient’s wishes are followed.

4. In developing policies and their operating procedures for DNACPR, organisations should agree clear mechanisms to identify the senior responsible clinician in complex cases.

5. The professional bodies should agree principles, processes and competencies which would allow organisations to develop local governance arrangements that ascribe roles and responsibilities clearly.

6. When somebody is starting to die they are at the start of a process. It is not an event. If this has been seen and understood by clinicians and those close to the patient and the patient is on one of the care pathways for the dying, this should be taken as a time for a DNACPR form to be completed.

Advance care planning and CPR discussions

1. Professional bodies and the commissioners and providers of health and social care services should promote the wider use of advance care planning - particularly outside the palliative care environment and when it is anticipated that a patient might die during an episode of care.

2. Professional organisations and royal colleges should emphasise the need for clinicians to be competent in communication and decision making that matches their exposure to these types of case and to record and review CPR decisions and share those decisions with the receiving clinician in any transfer or handover of clinical responsibility.

3. Individual clinicians should encourage patients to engage in advance care planning – including decisions about CPR - particularly when it is anticipated patients could require an episode of care during which they would be at risk of dying.

4. Clinicians should encourage patients who wish to refuse CPR to complete a valid ADRT, whenever there is an opportunity to do so. Sometimes this will not be possible in the acute setting where a patient has been admitted as an emergency, reinforcing the need for comprehensive ACP to take place whenever possible.
**Transfers within or between settings**

1. There should be clear procedures for senior clinical responsibility to be handed on when a patient moves between teams and settings. This should always be the case with a patient nearing the end of life or in cases where an arrest is anticipated.

2. This should involve an explicit conversation between members of the healthcare teams as part of the handover, including the ambulance crews, when a patient is being moved between settings.

3. The responsible clinician in any new setting should take a view about the benefits—or otherwise—of reviewing an existing decision. They should check that documentation matches the patient’s understanding of his or her CPR status as part of broader end of life care discussions.

4. It may not be appropriate to discuss the issue again with the patient if their circumstances have remained the same or have deteriorated in accordance with the anticipated progression of their illness or disease.

**Training and competences**

1. Competences and training around CPR assessment, shared decision-making and DNACPR discussions should be developed, particularly for doctors. These could be based on existing competencies and training for nurses.

2. There is a clear case for doctors and senior nurses who will adopt senior responsible clinician roles to be trained together. This should include communication skills training.

3. The skills and knowledge required to fulfil the role of senior responsible clinician in cases involving CPR decisions should be built into appraisal and revalidation processes.
12. Vignettes

The scenarios presented here illustrate difficulties in co-ordination and planning of care and treatment, including when a patient is transferred between settings.

Team-working in long-term or life-limiting conditions, elderly and palliative care could be extended to routinely include GPs and senior community nurses in multidisciplinary reviews. Such approaches may have helped to improve care planning in these scenarios.

We also outline the sort of conversation clinicians will regularly have with patients around CPR.

Scenario 1

Mr Chance had a common experience: his individual health problems were addressed, but the person with those problems was neglected.

Mr Chance, a 76-yr-old retired docker, was admitted to hospital with breathlessness. He was known to have heart failure, an implanted cardioverter-defibrillator, chronic lung disease and kidney failure. He also had “shadows” on his chest X-ray.

Cancer was suspected but treatment of his heart failure took priority over investigating this possibility. Over the next month in hospital his care was initially led by the medical team that admitted him.

The heart team transferred Mr Chance to their ward for specialist management.

Following a seizure that the doctors suspected may have been due to metastasis from his presumed lung cancer, an initial CT head scan was conducted but found to be normal.

Further scans with contrast were not carried out because of his kidney failure.

Mr Chance was already known to the kidney team who looked after this part of his care.

The respiratory team, who already knew about his lung shadows, saw him but they felt unable to advise on treatment until there was a firm diagnosis of cancer.

Mr Chance was only interested in going home and he was asking when this would be possible and about future care and treatment.

He was finally referred to palliative care for discharge planning

There was no indication of an overall care plan or recorded discussion with him about options.

Scenario 2

Mr Point was clearly dying but out of all the professionals involved in his care only the nurse looking after him noticed. Through patient and family eyes this was unacceptable.

Discussing his care with the primary care team and the responsible clinician (probably the GP or community nurse) could have avoided some of the failures in decision-making that meant there was little end of life care planning.
Mr Point was 71 and spent only two weeks of his final nine months at home. He was confused, had evidence of dementia, kidney failure, tongue cancer and malnutrition. He had been seen occasionally over the years with diabetes and heart disease.

Neither the diabetic nor cardiology teams knew that he was an inpatient. His wife was involved with decision-making as his capacity fluctuated. In hospital he had six teams involved in his care:

Surgeons treated the arterial disease in his legs, were the named team responsible and he was on a vascular ward despite repeated requests by the surgeons that he be under the care of a medical team.

The Kidney Team commenced dialysis during this admission, but whilst knowing him the longest, they did not consider his kidney failure to be his principal problems and so did not take over his care.

The oncology team saw him for his tongue cancer, but he was only fit enough for palliative radiotherapy. They did not feel that they should take over his care ‘now he was palliative’.

The gastroenterology team was involved because Mr Point constantly pulled out his nasal feeding tube and, percutaneous gastrostomy tube was requested. The gastroenterology specialist registrar felt that this would not be in his best interests, but could not find any member of the vascular surgical team to have a discussion with.

Older people’s services knew of Mr Point as they had been asked about him intermittently, but never made their own assessment as they felt that his medical needs were covered by the other medical specialties seeing him.

The palliative care team had been asked to help with symptom management and the ward nurse brought up the question of CPR, given Mr Point’s many life-limiting diseases. This was something she had raised with members of all the teams, none of whom was willing to give a view.

A DNACPR decision was recommended following a case conference of the palliative care and elderly care physicians. After a rapid deterioration, he died a few weeks later with his wife at his side.

It seemed that the teams had seen Mr Point as a series of health problems, but not as a dying man. The named clinician, a surgeon, felt unqualified to judge about CPR; none of the other senior doctors saw it as their responsibility.

Scenario 3

Mr Beat, a man in his 90s with dementia and chronic kidney failure, was admitted to hospital by the elderly care team because of infection and increasing frailty.

He was also well known to the kidney team. Following some improvement, he developed bleeding from the bowel, but it was decided, in consultation with the family, that this should not be investigated and it was agreed to arrange for him to be discharged home to die.

The healthcare team felt that Mr Beat was not going to die in the next few days and so he was not on an end-of-life pathway. Everyone agreed however that he was returning home to die and he was therefore not for CPR.
The senior responsible clinician was the elderly care consultant who was actively engaged in the discharge, as were palliative care, the kidney team and the community nursing team.

Mr Beat’s heart stopped during the journey home in a patient transfer ambulance.

CPR was started despite protests from the family. The ambulance technicians telephoned 999 for a paramedic crew who continued CPR.

When CPR was abandoned, there was confusion as to whether Mr Beat’s body should be taken to the hospital or home and whether the police should be called for advice.

A review of the case concluded there had been good communication between the clinicians but nobody told the ambulance technicians that Mr Beat was at risk of dying in transit.

The crew said a DNACPR form print-out was not valid once the patient had left hospital. There was no evidence of the emergency services having advance notification that this was a man returning home to die.

There was no instruction as to what to do with Mr Beat’s body should he die in transit.

The family’s views were ignored throughout because the crew said they ‘had to follow procedure’.

An everyday consenting discussion for CPR

We present below, a possible discussion as part of an overall consenting process for anticipated incidents.

“If you became worse, say you lost consciousness there are some decisions that we might have to take on your behalf because we wouldn't be able to ask you and given the choice it may be something you would not want.

“One of those that always concern us is what to do if your heart and breathing stop suddenly. Ordinarily we will go ahead and try cardiopulmonary resuscitation immediately, but you might not want us to try to do that. It is a major event if we need to do this, so would you like a conversation now to understand what is involved and the benefits, risks and burdens it will put on you and your body?”

Such a discussion preserves the default in favour of CPR. However it also provides the individual with the chance to consent or refuse if CRA is a real possibility without forcing conversation. It also helps normalise discussions about the realities and risks of life around death and dying.

The patient has an opportunity to refuse to have those discussions. It is better that the patient has the chance to discuss the issues and to refuse, rather than not to be informed and for decisions to be made without their input.
13. References

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3. Treatment and care towards the end of life: good practice in decision-making, General Medical Council, 2010
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8. Mental Capacity Act Code of Practice, Department of Constitutional Affairs, 2005
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30. Views of oncology patients, their relatives and oncologists on cardiopulmonary resuscitation (CPR): questionnaire-based study, R. Ackroyd et al. Palliative Medicine. 2007; 21(2): 139-44.


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14. Resources


Advance care planning

The differences between general care planning and decisions made in advance, NEoLCP (2012) - www.endoflifecareforadults.nhs.uk/publications/differencesacpadrt

Capacity, care planning and advance care planning in life limiting illness, NEoLCP (2012) - www.endoflifecareforadults.nhs.uk/publications/pubacpguide

Advance care planning: Support sheet 3 NEoLCP - www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3

Advance Decisions to Refuse Treatment, NEoLCP (2012) - www.endoflifecareforadults.nhs.uk/publications/pubadrtguide

Advance Decisions to Refuse Treatment: Support sheet 4, NEoLCP - www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet4

Documentation

Advance decisions to refuse treatment proforma, NEoLCP - www.endoflifecareforadults.nhs.uk/publications/adrtform

Background/Professional


Treatment and care towards the end of life: good practice in decision-making, GMC - www.endoflifecareforadults.nhs.uk/publications/gmceoltreatmentandcare
DNACPR decisions: who decides and how?

Best interests at end of life: practical guidance for best interests decision-making and care planning at end of life - www.endoflifecareforadults.nhs.uk/publications/bestinterestseolguide

Independent Mental Capacity Advocates: Factsheet 9, NEoLCP - www.endoflifecareforadults.nhs.uk/publications/factsheet9

For patients, carers and relatives

Dying Matters - www.dyingmatters.org

Training and education


National ADRT website - www.adrt.nhs.uk