

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

Integrated Adult Policy



Decision Making & Communication



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INTRODUCTION

Why is an integrated DNACPR policy needed?

Cardiopulmonary resuscitation (CPR) is a treatment that could be attempted on any individual in whom cardiac or respiratory function stops. Such events are inevitable as part of dying and thus, theoretically, CPR could be given to every patient when they die. It is therefore essential to identify patients for whom cardiopulmonary arrest represents the terminal event in their illness and for whom CPR would be inappropriate because it will not work and/or is not wanted by the patient.

The aim of CPR is to restore spontaneous breathing and circulation in a way that is sustainable for that patient. As with any treatment, CPR should only be offered if there is a clear expectation that its aim can be achieved

Where it is clear that CPR would not be successful (i.e. would not achieve *sustainable* spontaneous breathing and circulation) it should not be offered. There is a common lay-public misconception, possibly fuelled by media coverage, that CPR is *always* a potential life-saving treatment and that patients *always* have the right to be offered this treatment. Where it is clear in advance that CPR would not be successful it is essential that the information that CPR cannot be offered is clearly and sensitively shared with patients unless it is judged that the conversation would cause physical or psychological harm. Where a patient lacks capacity to engage with this conversation relatives/relevant others (those close to the patient) must be informed without delay where that is practicable and appropriate. A clinical decision that CPR will not work should be sensitively explained as part of a wider person-centred conversation about the patient's goals of care in the context of their current illness, and realistic expectation about future deterioration and dying.

It is also essential to identify those individuals who would not want CPR to be attempted in the event of an arrest and who competently refuse this treatment option. Some people may wish to make an advance healthcare directive about treatment (such as CPR) that they would not wish to receive in some future circumstance. Such directives must be respected as long as the decisions are informed, current, made without undue influence from others, and clearly apply to the current clinical circumstance.

This policy is intended to prevent inappropriate, contraindicated and/or unwanted attempts at CPR which are of no benefit and may cause significant distress to patients and families. A death managed with inappropriate CPR treatment is undignified and highly traumatic. When a patient dies at home or in a care home, an inappropriate CPR attempt may also involve the Scottish Ambulance Service paramedics and even the police, which can add greatly to the distress of the families and be upsetting for all those involved. This policy supports the wider aim of ensuring that a person's goals of care are known and respected at the end of life irrespective of whether they are being cared for in hospital, a hospice, a care home or in their own homes.

There is often confusion and uncertainty regarding CPR and the process of making advance decisions in which CPR will not be attempted. A consistent approach to decision-making, documentation and communication will help to avoid misunderstandings which can lead to harmfully distressing incidents for patients, families and staff. A single, integrated and consistent approach to this complex and important part of good end of life care is essential for all patients across Scotland.

Background

In 2010, in response to a specific recommendation from the Public Audit Committee (following the Audit Scotland publication "Review of Palliative Care Services in Scotland"), the Scottish Government developed and implemented a national integrated policy "Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decision Making and Communication".

In 2016, this policy was reviewed to reflect feedback and changes in the national good practice guidance (Decisions Relating to Cardiopulmonary Resuscitation – guidance from the British Medical Association, Royal College of Nursing and the Resuscitation Council (UK) – 2016). The policy also confirms the guidance within "Treatment and care towards the end of life: Good practice in decision-making" from the General Medical Council (2010). This policy takes into account relevant legal changes resulting from recent case law including; Montgomery vs Lanarkshire Health Board Scotland 2013 (https://www.supremecourt.uk/cases/uksc-2013-0136.html); Tracey v Cambridge University NHS Trust and the Secretary of State for Health. (https://www.judiciary.gov.uk/wp-content/uploads/2014/06/tracey-approved.pdf); and Winspear vs City Hospitals Sunderland NHS Trust (https://www.bailii.org/ew/cases/EWHC/QB/2015/3250.htm)

Using the integrated DNACPR policy

The advice in this policy should be used in conjunction with the revised NHSScotland DNACPR form, decision-making framework and patient information leaflet, which can all be found within and appended to this policy. The purpose of the policy is to provide guidance and clarification for all staff working within NHSScotland regarding the process of making and communicating decisions about CPR. Further information is available at http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/DNACPR. It is a duty of care to ensure that, as far as possible, an advance DNACPR decision is communicated in a way that rapidly informs the emergency decisions of healthcare professionals when a patient's pulse and breathing have stopped. A consistent and instantly recognisable document is essential and the NHSScotland DNACPR form is recommended as best practice. An advance DNACPR decision can also be indicated within the electronic Emergency Care Summary using the **Key Information Summary (KIS¹)**. Services involved in the assessment of acutely unwell patients in the community or in hospitals should ensure that all frontline staff has access to, and knowledge of the KIS.

¹ http://www.snughealth.org.uk/gp-software/key-information-summary

For children and young people, the wider anticipatory care document contained within the Children's and Young Person's Acute Deterioration Management (CYPADM²) policy is more relevant and appropriate to use for communicating advance decisions on emergency treatment and care such as CPR. However, it is acknowledged that there may be patients for whom use of the CYPADM remains appropriate well past the 18th birthday.

When a decision about CPR is discussed, made and recorded, clinicians should try to be clear about the basis for the decision. For example, it may be made with and/or for:

- 1. A person who is at an advanced stage of dying from an irreversible condition, so CPR is contraindicated.
- 2. A person who has advanced illness and deteriorating health such that CPR will not work.
- 3. A person for whom CPR is a treatment option with a poor or uncertain outcome.
- 4. A person for whom CPR is quite likely to restore them to a quality of life that they would value.

In the first two of these CPR will not be successful and should not be offered or attempted. In the third and fourth, the wishes of the patient are paramount. In the context of an acute illness or acute exacerbation or relapse of a chronic condition, consideration of an anticipatory decision about CPR should prompt also consideration of what other supportive treatments or higher-level care may or may not be needed by, wanted by or appropriate for each individual patient. There should be early involvement of senior, experienced clinicians in decision-making in such situations.

Decisions relating to CPR – guidance from the BMA, RC(UK) and RCN 3rd ed (1st revision) 2016

Within this policy, the term "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) is used rather than "Do Not Attempt Resuscitation" (DNAR) to help clarify for patients, families and professionals that this policy refers solely to cardiopulmonary resuscitation (CPR) in the event of a cardiac or respiratory arrest. DNACPR is also specifically used rather than "Allow Natural Death" (AND) as it does not mean "do not treat". Indeed, other aspects of emergency care e.g. analgesia, antibiotics, suction, treatment of choking, treatment of anaphylaxis, non-invasive ventilation or even treatment in an Intensive Treatment Unit (ITU) may be appropriate for patients with DNACPR decisions. Where patients are admitted to hospital or a hospice acutely unwell, or become medically unstable in their existing home or community healthcare or social care setting, their CPR status should be considered as soon as is reasonably possible if a cardiac or respiratory arrest can be anticipated. It is both good practice and may be legally required to consider and communicate CPR decision-making within the context of exploring goals of care and appropriate levels of escalation of treatment with the patient, any welfare attorney/welfare guardian or others close to the patient. Sometimes patients are not medically unstable, but it is clear that advanced illness, significant frailty and/or co-morbidity are such that they are at risk of deterioration and therefore death would not be unexpected. For these patients, it is important

² http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/CYPADM

to consider, discuss and document advance decisions about goals of care and treatment plans which must include a decision on whether CPR should be attempted. An advance DNACPR decision should be recorded in the KIS along with details of other available treatment options when the person is in, or being discharged back to, a community environment.

A number of Health Boards are using and developing forms and templates for documenting options for emergency treatments or levels of care (e.g. "ward level care", "intensive care", etc.) that would or would not be appropriate and/or wanted in a sudden acute deterioration situation. It is recommended that the NHSScotland DNACPR form be used to complement any locally developed Anticipatory Care Plans (AnCP), Treatment Escalation Plans (TEP) or Emergency Care and Treatment Plans (ECTP).

When no explicit decision has been made about CPR before a cardiopulmonary arrest occurs, and the express wishes of the patient are unknown, it is presumed that staff will initiate CPR. However "there will be some people for whom attempting CPR is clearly inappropriate; for example, a person in the advanced stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful, but for whom no formal CPR decision has been made and recorded. Also, there will be cases where healthcare professionals discover patients with features of irreversible death – for example, rigor mortis. In such circumstances, any healthcare professional who makes a carefully considered decision not to start CPR should be supported by their senior colleagues, employers and professional bodies". It is essential to document clearly in the clinical notes a detailed account of the assessment and rationale for the clinical decision not to attempt CPR in this situation, and clinicians must be supported to do this by colleagues and line managers.

Throughout this document, the term "patient" is used to refer to the person for whom the CPR decision-making process is intended but it is acknowledged that this policy may be relevant for people in community care and residential settings who may not necessarily regard themselves as "patients".

Throughout this document, the term "**relevant others**" is used to describe those close to the patient such as the patient's spouse, partner, relatives, carers, named person, representative, advocate, welfare attorney or welfare guardian.

³ Section 8 Decisions relating to cardiopulmonary resuscitation revised 3rd edition – Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2016).

OBJECTIVES OF THE POLICY

- 1. To ensure a consistent and integrated approach to CPR decision-making, documentation and communication across Scotland for all patients in all care settings (including the patient's own home or care home) in line with national good practice guidance (BMA 2016).
- 2. To ensure that decisions regarding CPR are made according to:
 - whether CPR could be successful in achieving sustainable life
 - the clinical needs of the patient
 - the patient's wishes and their judgment of the overall benefit provided by CPR where it might be successful
 - current ethical principles
 - legislation such as the Human Rights Act (1998) and Adults with Incapacity (Scotland) Act 2000
 - international human rights instruments such as the European Convention on Human Rights and the UN Convention on the Rights of Persons with Disabilities.
- 3. To make DNACPR decisions transparent **and** open to examination.
- 4. To ensure that a DNACPR decision is communicated to all relevant healthcare professionals and services involved in the patient's care.
- 5. To avoid inappropriate CPR attempts and support good end of life care in all health, social and home care settings.
- 6. To ensure staff, patients and their relevant others have appropriate information on making advance decisions about CPR and that they understand the process, and that patients and relevant others understand their rights if they are in disagreement with the care team.
- 7. To clarify that patients, and their relevant others will be sensitively informed of, but will not be asked to make a decision about, CPR when it is not a treatment option that would work.
- 8. To clarify that patients, and their relevant others, cannot demand any treatment (such as CPR) that is judged to be clinically inappropriate.
- 9. To clarify that patients, and their relevant others will not be asked to make an advance decision about CPR when the circumstances of a possible cardiopulmonary arrest cannot be anticipated and therefore informed discussion about CPR harms and benefits cannot take place.
- 10. To encourage and facilitate honest, sensitive, appropriate and realistic discussion with patients and their relevant others about CPR in the context of their individual situation and goals of care.
- 11. To clarify the decision-making process about CPR for clinical staff caring for people who have communication difficulties and other vulnerable groups.

SCOPE OF THE POLICY

This policy is specifically about cardiopulmonary resuscitation (CPR), meaning treatment given with the aim of restoring sustainable spontaneous circulation and breathing when both have stopped. It does not indicate an advance decision about any other emergency treatment and/or care, including procedures that are sometimes loosely referred to as "resuscitation" such as rehydration, blood transfusion, intravenous antibiotics etc.

This policy applies to all NHSScotland Staff and the care of adult patients in all health and social care settings within the remit of NHSScotland. Independent care organisations and facilities are encouraged to make use of this NHSScotland policy for the benefit of their patients.

Due to the changing population of the prisons and the increasing number of patients who may die in custody, the policy also applies to all staff within Scottish Prisons including the two private prisons. Completion of a DNACPR form will be communicated to the relevant personnel within the prison, with the Governor having local responsibility regarding this. Communication with the patient in custody and their family regarding their health condition will remain the responsibility of NHS Staff. Local systems should be established to ensure appropriate communication between the NHS and Scottish Prison Service teams.

It is implicit in this policy that generally recommended practice may be altered in exceptional circumstances according to clinical judgement. In such a situation, clear documentation in the case notes is of prime importance to record actions and discussions, and to explain and justify the decision-making process.

CONSIDERATION OF THE OUTCOME OF CPR

It is not unusual for patients and their relevant others to have unrealistic expectations of the success of CPR and also its consequences. Where CPR is a treatment option, realistic, honest and individualised explanations of the traumatic nature of the treatment and the expected outcomes in terms of survival to discharge should be included in discussions with patients and those close to them. This information is an essential part of informed, shared decision-making.

Consideration of the outcome of resuscitation should be as realistic as possible and should take into account the clinical condition and functional status of the patient, the likely cause of the anticipated arrest, and also the environment in which the patient is being cared for. **Making this complex clinical judgement is a core responsibility of every experienced clinician.**

A clinical DNACPR decision should be based on the judgement that effective CPR will not achieve **sustainable** spontaneous breathing and circulation for the individual patient rather than any judgement about the quality of the life that may be achieved. It is recommended that such **clinical decisions** be made considering the circumstance of a prolonged resuscitation. There may be some situations, such as critical or intra-operative care, in which the likely cause of the cardiac arrest is easily treatable and the advance decision-making should therefore reflect this. It may be appropriate to temporarily suspend a documented DNACPR decision for the duration of an operation or procedure where a potentially reversible cardiac or respiratory arrest can be anticipated. Where the documented DNACPR decision is a clinical one made because CPR will not be successful, the reasons why this decision would not apply to the perioperative period must be carefully considered and sensitively shared with the patient and their relevant others. Where a DNACPR decision is documented because the patient would not wish to have CPR, the patient's advance refusal must be carefully considered in the context of a peri-operative cardiac arrest and a plan agreed with them and/or their relevant others. Patients with a DNACPR decision in place must be referred to the anaesthetist as early as possible prior to a planned operative procedure to enable these discussions to be held and fully documented. The Association of Anaesthetists of Great Britain and Ireland (AAGBI) has published specific guidance on management of CPR decisions in the perioperative period (see www.aagbi.org/ publications/publications-guidelines/A/F).

SUCCESS AFTER CPR

The number of people who survive cardiac arrest following the administration of CPR remains relatively low. For cardiac arrest occurring within hospital, the chance of surviving to hospital discharge varies considerably and depends on many factors, including existing co-morbidities and the cause and circumstances which led to the event. Studies indicate that the average survival to hospital discharge is 15-20% (Sandroni et al 2007; Meaney et al 2010; Girotra et al 2012; Nolan et al 2014).

When cardiac arrest occurs out of hospital and CPR is attempted, average survival to hospital discharge is lower, usually 5-10% (Nolan et al 2007; Berdowski et al 2010; Perkins & Cooke 2012). The probability of success depends on many factors such as underlying cause, how soon CPR is commenced, and the availability of resuscitation equipment and appropriately trained personnel. We should also recognise that the chances of survival after cardiac arrest will be much lower in patients with life-limiting conditions than the unselected populations quoted in the literature above.

Throughout this policy the term "successful" in the context of a **clinical decision** about CPR, is used to mean CPR which achieves sustainable spontaneous breathing and circulation. However, while success after CPR may be measured clinically by immediate sustainable survival, it is often more meaningfully understood by patients and their relevant others to indicate a return to a quality of life that the patient would find acceptable. Where a patient already has a life-limiting illness, the best that could be hoped for from "successful CPR" is return to that state or more often a reduced level of physical and mental health and function. During CPR, rib fractures and hypoxic brain injury are significant risks. There is a great potential for inflicting distress, harm and suffering in an attempt to prolong some level of survival. The likelihood of success as measured by survival needs to be viewed in this context. Intensive Care is not an option which can change outcome when the cause of arrest was an underlying life-limiting or terminal illness which cannot be improved. In patients with significant life-limiting illness the balance of potential benefits and burdens of any intervention must be considered with the patient and their relevant others before any advance decision can be made.

It is not possible to give guidance for all patients and situations. Individual clinicians should use their knowledge of their patient and natural history of their current underlying health problems to decide what outcomes are likely and when CPR would not work or would lead to outcomes that are not in line with patient wishes. As set out later, though, clinicians must not base their decision on their subjective opinion of the patient's "quality of life".

THE PRINCIPLES OF MAKING A DNACPR DECISION

The circumstances of cardiopulmonary arrest must be anticipated

If the circumstances of a cardiopulmonary arrest cannot be anticipated, it is not possible to make a CPR decision that can have any validity in guiding the clinical team. In order to make an informed decision about the likely outcome of CPR it is essential to be able to think through the likely circumstance(s) in which it might happen for the patient. It is an unnecessary and cruel burden to ask patients or relevant others about CPR when it seems unlikely that circumstances would occur where the patient would require CPR. This should never prevent discussions about resuscitation issues with the patient if they ask to have them.

It should be recognised for some patients with life-limiting illness that the level of frailty and/ or co-morbidities may be such that an acute deterioration or a sudden death would not be unexpected. For such patients it may be reasonable to make an advance decision about CPR through sensitive exploration of their goals of care and wishes for emergency treatment even though a cardiorespiratory arrest is not imminently expected.

When CPR would not be successful it should not be offered as a treatment option

Although patients should not be offered CPR when it is clear it will not be successful, open and honest communication is essential to ensure the patient and relevant others have the opportunity to be made aware of the patient's condition, and to be informed of any clinical decision that CPR would not be successful and therefore cannot be offered as a treatment option. Sensitively disclosing the realistic risks of acute deterioration and death allows helpful clarification of the patient's goals of care, end-of-life care wishes and choices around escalation of emergency treatment options. It also gives the patient the opportunity of seeking a second opinion. It is essential to ensure and to document that the patient understands why CPR is not a treatment option for them. Recent case law has clarified that there should be a presumption in favour of consulting the patient, including informing the patient that a clinical DNACPR decision has been made, and the concern of causing simple distress is no longer a justifiable reason to avoid involving the patient. However, it was also recognised that it may be inappropriate to involve the patient if it is very clear that the conversation would cause the patient physical or psychological harm. In this situation it is essential that the rationale for not informing the patient is clearly documented along with a plan to review the patient's ability to accept the information without harm.

"....doctors should be wary of being too ready to exclude patients from the process on the grounds that their involvement is likely to distress them. Many patients may find it distressing to discuss the question whether CPR should be withheld from them in the event of a cardio-respiratory arrest. If however the clinician forms the view that the patient will not suffer harm if she is consulted, the fact that she may find the topic distressing is unlikely to make it inappropriate to involve her. I

recognise that these are difficult issues which require clinicians to make sensitive decisions sometimes in very stressful circumstances. I would add that the court should be very slow to find that such decisions, if conscientiously taken, violate a patient's rights under article 8 of the Convention." (Tracey v Cambridge University NHS Trust and the Secretary of State for Health 2014 para 54).

In the situation when death is expected as an inevitable result of an underlying disease, progressive frailty and/or co-morbidities, and the clinical team is as certain as they can be that CPR would not be successful in achieving sustainable life, it should not be attempted. *In this situation CPR is not a potential life-prolonging treatment and as such, it may only cause harm by creating a death that is highly medicalised, traumatic, undignified and potentially painful and distressing.* In this situation it is not appropriate to offer CPR as it is not a treatment option. However it is essential to share this information *as part of* discussions with patients and/or their relevant others to explore goals of care and establish anticipatory treatment plans. Where there is disagreement a second opinion may be offered. Although this is recommended as good practice, a second opinion is not a legal requirement where the clinical decision that CPR will not work is endorsed by the multidisciplinary team.

National good practice guidance clarifies that, in most cases, people should be informed, but for some, for example those who know that they are close to the end of their life, such information may be so distressing as to cause the person to suffer physical or psychological harm.⁴

Appropriate and sensitive communication and the provision of information are an essential part of good patient care

Good anticipatory care planning should address the circumstances in which CPR might be considered an integral part of escalation/emergency care planning for patients who are deteriorating or are clearly at risk of a sudden deterioration. The timing and nature of conversations about CPR are a matter of judgement for the clinical team. Healthcare professionals should be aware that it is rarely appropriate to discuss DNACPR decisions in isolation from other aspects of escalation/emergency treatment planning in terms of clarifying goals of care and exploring end-of-life care choices. Decisions about CPR are only one of many important aspects of a patient's anticipatory emergency care planning. As such, the need to make an advance decision about CPR can prompt conversations which can help patients achieve a better understanding of their individual situation and provide reassurance that their wishes about realistic treatment options and for their end-of-life care will be respected.

The patient should be given as much information as they wish about their situation. This includes information about CPR in the context of their own illness and sensitive communication around dying and end-of-life issues. Relevant others can be given this information if the patient agrees. It is not the professional's responsibility to decide how much information the patient should receive, their task is to find out how much the patient wishes to know or can understand. The professional

⁴ Decisions relating to cardiopulmonary resuscitation revised 3rd edition – Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2016).

must ensure that they do not give selective information; all information that may be relevant to the CPR decision should be provided as requested. As with all discussions and decisions about end-of-life care staff must be aware that some patients will want the support of a trusted religious/spiritual advisor during or after conversations about CPR.

Such discussions can result in upset and even anger for patients and their families and are often uncomfortable for healthcare staff, but anticipation of this should not prevent open and honest communication. Where a DNACPR decision is made on clinical grounds (when CPR will not work) there should be a presumption in favour of informing the patient of this decision, **in the context of their goals of care and realistic treatment options**. There will be circumstances when clinicians judge that giving information and explanations about CPR decisions would be likely to cause physical or psychological harm to the patient. Faced with such a situation, clinicians should make the decision about CPR that is clinically indicated and record fully their reasons for not explaining it to the patient, including a clear rationale for the judgment of potential physical or psychological harm. They should also ensure that there is ongoing active review of the decision and of the patient's ability to accept explanation of the decision without such harm, so that the patient is informed at the earliest appropriate opportunity. Many patients may find it distressing to discuss a CPR treatment decision; however, if the clinician forms the view that the patient will not suffer physical or psychological harm when consulted, it is appropriate to bring the topic into conversation.

Where CPR will not be successful and the patient lacks capacity to engage in such a conversation those close to the patient (relevant others) must be informed of the decision without delay. It is essential that this conversation happens as part of a wider explanation of the patient's clinical condition which enables exploration and agreement of the goals of care. Achieving a shared understanding of the patient's clinical condition and goals of care should be the aim of the conversation rather than simply to inform of a DNACPR decision. This is a complex conversation and will rarely be appropriate to have by telephone⁵. However there may be some well-considered situations where this is clearly the only practicable and appropriate way to achieve such a shared understanding. Clinicians may find themselves in a situation in which they take a conscientious decision that it is not practicable or not appropriate to inform those close to the patient immediately or for the conversation to take place in person. For example, they may believe that contacting and informing them at a particular time will cause them to suffer harm. Where it is not practicable or appropriate to have this conversation with relevant others the reasons must be documented along with a plan to review this.

There are clear benefits for patients and their relevant others in being aware of and understanding the positive purpose of documenting a CPR treatment decision on a specific form and the reassurance that it may prevent an inappropriate, traumatic and distressing emergency response by ambulance crews and police. It is important for patients at home and their carers to be reassured that a call for urgent assistance will be responded to appropriately by whichever service responds.

⁵ Section 5.3, Decisions relating to cardiopulmonary resuscitation revised 3rd edition – Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2016).

Discussions about CPR are sensitive and complex and should be undertaken by healthcare staff with the relevant knowledge of the patient's situation and the experience to recognise and respond to the patient's information needs. It is recommended that staff have formal communication skills training in preparation for this clinical responsibility. Any decision-making processes and/or discussions about CPR should be documented in the medical, nursing or multidisciplinary notes.

Quality of life judgements should not be part of the decision-making process for healthcare professionals

This policy supports the view that clinical decisions should be based on immediate health needs, and not on professional opinion on a person's quality of life. This is primarily because opinions on quality of life made by health professionals are very subjective and often at variance with the views of the patient and relevant others. The UN Convention on the Rights of Persons with Disabilities sets out that discrimination on the basis of disability is a breach of the Convention. Article 25 provides that States shall "prevent discriminatory denial of health care ...on the basis of disability."

Where CPR may be medically successful in achieving sustainable life, it is essential to know the patient's fully informed views on the burdens and benefits of this treatment and its likely outcome for them. Where CPR is being offered as a realistic treatment option, healthcare professionals must be clear that they are providing accurate and understandable information about the potential benefits and burdens of this treatment for this patient.

Where no advance decision about CPR has been made, there should be an initial presumption in favour of providing CPR

When no explicit decision has been made about CPR before a cardiopulmonary arrest occurs, and no expressed wishes of the patient are known, it should be presumed that staff would initiate CPR for the patient. However, although this should be the initial presumption, there will be some patients for whom attempting CPR would clearly not be successful, for example a patient in the final stages of a terminal illness where death is imminent and unavoidable. Where CPR will not work it should not be attempted. Any healthcare professional that makes and documents a carefully considered decision not to start CPR in such a situation should be supported by their senior colleagues, employers and professional bodies.

ADVANCE DECISIONS ABOUT CPR TREATMENT

Advance decisions about CPR can be difficult and can cause considerable emotional distress but, when discussed in the context of goals of care and choices about available treatment options, they can also be extremely reassuring and a huge relief for some patients. There is evidence that patients experience conversations about DNACPR as positive and empowering when they happen within the context of wider discussions about emergency care planning and end of life care goals (http://www.palliativecarescotland.org.uk/content/publications/23.-Patient-and-family-experiences-of-DNACPR-discussions---an-integrative-review-of-the-literature.pdf). The appropriateness of CPR should always be considered on an individual patient basis. There is never a justification for blanket policies to be in place. An advance decision that CPR should not be attempted can be made if either of the following is relevant:

A patient makes a competent advance refusal

- When CPR is not in accord with the recorded, sustained wishes of the patient who has capacity for that decision.
- When CPR is not in accord with a valid applicable advance healthcare directive (living will).
 A patient's informed and competently made refusal which relates to the circumstances which have arisen should be respected.

CPR treatment would not be of overall benefit for the patient

- When a patient's condition indicates that effective CPR would not be successful in achieving sustainable spontaneous breathing and circulation.
- When the patient lacks capacity and the healthcare team, in discussion with the patient's
 relevant others, agree that the benefits of medically successful CPR are likely to be
 outweighed by the burdens of that treatment, and/or that they are as certain as they can be
 that the patient would have regarded the quality of the sustainable life that is likely to be
 achieved as unacceptable.

When CPR may be successful it is important to assess whether the patient has the capacity to be involved in a decision about the overall benefit of such a treatment. If capacity is present, the issue should be broached with the patient in the context of their individual goals of care and exploration of their wishes for realistic emergency treatment options and end-of-life care choices. Where possible the patient should be asked whether they have thought about these issues and would wish further discussion. If the patient declines, then it is appropriate to make the decision without consulting the patient further. It would be appropriate to ask the patient if there is anyone else they would wish to be consulted and also to establish if they would or would not wish to be informed of any care decision that is reached. The importance of clear documentation of all of these discussions cannot be emphasised strongly enough.

If the patient does not have capacity for the CPR decision, then the principles of the Adults with Incapacity (Scotland) Act 2000 apply⁶. Where CPR might be successful in achieving sustainable life, a decision about whether the benefit of CPR would outweigh the harms and burdens for that patient must be discussed and agreed between that healthcare team and the patient's relevant others. Where there is a legally appointed proxy decision-maker (welfare attorney or welfare guardian) they must be involved in the decision-making process. Relevant information should be shared with those close to the patient (See Appendix IV).

Care should be taken in assessing capacity, and a specialist assessment may be helpful. Where a person's communication may be impaired, they should be provided with whatever assistance may be needed to assist communication. Further guidance is available in Chapter 3 of the Mental Welfare Commission's guidance document on Consent to Treatment.⁷

Even if a person does not have capacity, attention should be paid to their past and present wishes, and proper efforts should be made to establish these.

RESPONSIBILITY FOR DECISION-MAKING: PROFESSIONAL

The overall responsibility for making an advance decision about CPR rests with the senior clinician (doctor or nurse) who has clinical responsibility for the patient during that episode of care. This will usually be the consultant (in general hospitals) or the general practitioner (in the community-based hospitals, care homes or the patient's home). However, it is also reasonable for other grades of suitably qualified and experienced medical and senior nursing staff to take responsibility for this decision provided that they accept that they have clinical responsibility for the patient during that care episode. At a local level, multidisciplinary teams must be clear about which members of their team are able to take on this responsibility. A decision about CPR should be made in consultation with other relevant members of the care team who have knowledge of that patient.

Where a DNACPR decision has been established with certainty the healthcare professional documenting the decision can sign the form in any hospital or community setting but the decision must be fully discussed and agreed with the responsible senior clinician who should then sign the form at the next available opportunity.

⁶ http://www.mwcscot.org.uk/the-law/adults-with-incapacity-act/principles-of-the-act/

⁷ http://www.mwcscot.org.uk/media/51774/Consent%20to%20Treatment.pdf

RESPONSIBILITY FOR DECISION-MAKING: PATIENTS AND THEIR RELATIVES/CARERS

A competent patient can:

Make an advance refusal of CPR even if CPR is deemed to be likely to be medically successful.

- They do not have to give a reason for such refusal.

Accept (consent to) CPR if it is offered as a treatment option.

- In the event of a cardio-respiratory arrest, CPR must only be offered if it is likely to be successful in achieving **sustainable** life for that patient.

A patient cannot:

Demand CPR if it is clinically judged that it would not be medically successful in achieving sustainable life for that patient.

- Healthcare staff cannot be obliged to carry out interventions that they judge are contraindicated/may be harmful.
- If agreement cannot be reached after sensitive and open discussion, a second opinion should be offered. Obtaining a second opinion is considered good practice but is not legally required if the multidisciplinary team is in agreement.

Where a patient lacks capacity for involvement in advance decisions and has no legally appointed proxy decision maker (welfare attorney/welfare guardian/person appointed under an intervention order with relevant powers) (see Appendix IV):

- The responsibility for deciding if CPR would be of overall benefit for the patient lies with the lead clinician for the patient.
- In order to establish this decision, it is good practice, and also a requirement, to consult with those close to the patient, as well as taking what steps are possible to establish the wishes of the patient.
- Family/carers/next of kin do not have decision-making rights or responsibilities in this circumstance. Discussion with the family has the primary aim of clarifying the patient's prior views/wishes, and what they feel the patient would have chosen in this situation.
 Discussion should also enable family to express their own views on what they feel would be of benefit for the patient.

Where a patient lacks capacity for involvement in advance decisions and a proxy decision maker (legally appointed welfare attorney/welfare guardian/person appointed under an intervention order with relevant powers) has been identified (see Appendix IV):

The proxy decision maker can, if they have powers in relation to medical consent;

- Accept (consent to) CPR if offered.
- Refuse to consent to CPR if offered. However, if the treating doctor believes that offering CPR would be justified, the doctor can use the procedure in section 50 of the Adults with Incapacity Act, to obtain a second opinion from a doctor nominated by the Mental Welfare Commission. This opinion is final unless appealed to the Court of Session. (Formally, this procedure applies to the actual treatment, not the granting of a DNACPR certificate. However, if the discussion about a DNACPR certificate makes clear that the guardian or attorney does not agree with the doctor's wish to treat in appropriate circumstances, this procedure may be invoked.)

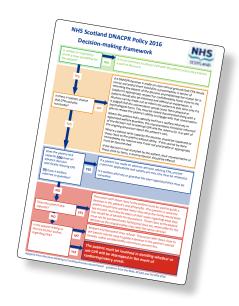
The proxy decision maker cannot:

 Demand CPR if it is clear that CPR will not be successful in achieving sustainable life for the patient.

However, the proxy decision maker must be consulted about any advance decision to give or to not give CPR. If agreement about a decision not to offer CPR cannot be reached after sensitive discussion, a second opinion should be offered, although this is not a legal requirement where the multidisciplinary team is in agreement.

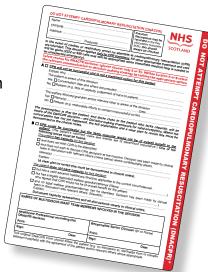
THE DECISION-MAKING FRAMEWORK

The NHSScotland decision-making Framework is adapted from the Decision-making Framework in the guidance from the BMA, RC (UK) and the RCN (2016) and should be followed to enable you to make a decision about cardiopulmonary resuscitation. A shortened guidance note is available on the second page of the Framework, however the Framework (viewable in Appendix II) should be viewed with the additional information provided in Annex A of this policy.



THE DNACPR FORM

The DNACPR form in itself is not legally binding. It should be regarded as evidence that an advance clinical assessment and decision has been made and recorded to guide immediate clinical decision-making for those who may encounter the patient in the event of a cardiopulmonary arrest or expected death. When a DNACPR form is completed it is essential that the decision-making process and any relevant discussions and conversations are documented clearly and fully in the clinical notes. Where conversations with the patient and/or their relevant others have not taken place, the reasons for this must be clearly documented in the clinical notes with a plan to review this.



A clinical team that knows the patient and is certain of the background to the decision should not regard the decision as invalid simply because a form has been incorrectly completed. If the patient is not known, and an incorrectly completed form is present, advice should be sought from other sources (e.g. KIS, or the contact details on the form).

The presence or absence of a DNACPR form should not override clinical judgement about what will be of overall benefit to the patient in an emergency (e.g. choking, anaphylaxis, sepsis etc.).

Where CPR will not work or is not wanted a DNACPR form should be completed following the appropriate communication with the patient or relevant others, and the decision communicated to those involved in the patient's care. It is important that all relevant healthcare and social care professionals involved in the patient's care are aware that a decision not to give CPR has been made and documented on a DNACPR form. In order to facilitate rapid communication of the decision in an emergency, the original DNACPR form should be immediately accessible wherever the patient is being cared for.

When a patient is moving to a different care setting, a photocopy of the original form may be retained for medical record audit purposes. A line should be drawn through the photocopy to make it clear that it is not the valid DNACPR form, before it is filed in the records. The original form should go with the patient.

When a patient is at home, they and/or their relevant others must have been made aware of the DNACPR form for it to be of use in an emergency situation. Where this information has not been given due to the likelihood of this causing physical or psychological harm to the patient, the form must not be sent home with the patient. The patient's GP should be supported to record the advance decision that CPR is not a treatment option within the electronic KIS record with an explanation of the patient and family's understanding.

When a patient is being transferred to a different care setting, it is necessary for the ambulance crew involved to have the original DNACPR form, or have verbal/electronic confirmation that the DNACPR form exists. The crew must also be informed of whether there has been discussion with the patient and family about the DNACPR form prior to the journey. This ensures compliance

with the Scottish Ambulance Service End-of-Life Care Policy (2014). It is important that a preferred destination and point of contact is documented on the form in case the patient should die whilst in transit. If there is no destination documented the ambulance crew will take the patient's body to the nearest A&E department or as otherwise advised by their clinical advisor.

The Out of Hours Service must be made aware of the existence of the DNACPR form using the KIS when the patient is being cared for in the community. When a DNACPR decision is reversed, the KIS record must be updated as soon as is reasonably possible.

When a DNACPR decision is being reversed, this must be signed and dated in the review box but the form should also be clearly scored through with a black pen and the word "REVERSED" written across it. The invalid form should then be filed in the back of the clinical notes. Where paper-light/electronic systems are in use, Boards must ensure there is a consistent and robust way of communicating the DNACPR decision and clearly show where it has been reviewed and/ or reversed.

There will be exceptional situations where a patient for whom CPR would clearly not work is being discharged home without a DNACPR form because the conversation would cause harm. It is essential that this information is promptly and effectively communicated to the patient's GP so that their KIS can be updated to reflect this situation. DNACPR guidance within the KIS or provided verbally by a clinician who knows the patient (e.g. GP or district nurse) should be acknowledged and acted on appropriately when a DNACPR form is not available in the emergency situation.

REVIEWING THE DECISION

The revised guidance clarifies that review of CPR decisions must be done on a clinically appropriate and individualised basis. A timeframe for review of the initial decision should reflect the variability of the patient's clinical situation. Patients, who are continuing to deteriorate with one or more irreversible conditions and with no prospect of recovery to a point where CPR might work, do not need to have the DNACPR decision reviewed.

Local clinical teams have a responsibility to ensure that CPR status is checked and clarified along with other aspects of anticipatory emergency care and treatment planning at every handover, safety huddle, ward round or multidisciplinary meeting.

When the lead clinician changes due to transfer or discharge, any DNACPR decision must be reviewed as soon as is reasonably possible, but it is assumed that the existing decision will remain valid meantime.

Where the team are notified of the appointment of a welfare guardian or welfare attorney after a DNACPR is in place, that person should be notified of the existence of the form, and consideration given to a review involving them.

ANNEX A:

Supporting Information when making CPR decisions and completing a DNACPR Form

To be viewed with the NHSScotland Policy 2016 Decision-making Framework for Cardiopulmonary Resuscitation (CPR) Decisions and NHSScotland DNACPR form

Is cardiac or respiratory arrest a clear possibility for the patient?



If it is not possible to anticipate circumstances where cardiopulmonary arrest might happen there is no advance decision to make about CPR.

- Do not initiate discussion about CPR with the patient or relevant others.
- The patient and relevant others should be informed that they can have a discussion, or receive information, about any aspect of their treatment. If the patient wishes, this may include information about CPR and its likely success in different circumstances.
- Continue to communicate progress to the patient and relevant others if the patient agrees.
- Review only when circumstances change.
- In the event of an unexpected cardiopulmonary arrest there should be a presumption that CPR would be carried out (unless it is unequivocally clear at the time that CPR would not work).
- No DNACPR form should be completed.
- When a patient has strong views about treatments such as CPR that they would not wish
 to receive in certain future circumstances they should be supported to develop an advance
 healthcare directive.

Is cardiac or respiratory arrest a clear possibility for the patient?



YES

DNACPR decisions are possible in advance where a patient is felt to be at risk of a cardiopulmonary arrest either as a sudden and acute event as a result of existing significant illness or because they are identified as imminently dying. Where a cardiopulmonary arrest is not imminently expected it may still be reasonable to make an advance decision about CPR where a patient's death would not be unexpected due to advanced illness, significant frailty and/or co-morbidities.

Is there a realistic chance that CPR could be successful?



YES

If the team is as certain as it can be that CPR would realistically have a possibility of a medically successful outcome (achieve sustainable life) the next decision is whether the patient has capacity to take part in this discussion and fully comprehend the implications of the decision to consent to or refuse CPR being given.

Patients with capacity are able to understand their situation and the consequences of their decisions. Adults should be presumed to have capacity unless there is evidence to the contrary. An assessment of capacity should relate to the specific decision the patient is being asked to make and to their ability to fully comprehend their situation and the implications of their decision. All reasonable support to aid decision making should be offered.

Patients who are judged to lack the capacity to make decisions about their care should be managed under the principles of the Adults with Incapacity (Scotland) Act 2000.

If the patient has capacity for this decision:

- Sensitive, honest and realistic discussion about CPR and its likely outcome should be undertaken with the patient in the context of goals of care by an experienced member of the clinical team unless the patient makes it clear they do not wish to have this discussion.
- Continue to communicate progress to the patient and relevant others if the patient agrees.

If the patient does not have capacity for this decision:

- Where it is practicable and appropriate, a previously appointed legal welfare attorney/guardian must be involved in the decision-making process for the patient with the help of sensitive and honest discussion with experienced members of the clinical team.
- When no legal proxy has been appointed for the patient, the clinical team should make reasonable efforts to understand the person's own preferences, and enquire about the patient's previously expressed wishes from the relevant others. The clinical team have responsibility for making the most appropriate decision based on whether the benefits to the patient offered by CPR outweigh the likely burdens/harm created by the treatment. Those close to the patient must be enabled to make their views about this known as part of the decision-making discussions where practicable and appropriate.
- Continue to communicate progress to the relevant others.

Document this discussion in the relevant clinical notes detailing the circumstances that any decision relates to and who was involved in the decision-making process.

Complete DNACPR form if appropriate.

Review if and when clinically appropriate and if circumstances change for the patient.

In the event of a cardiopulmonary arrest, act according to the patient's previous wishes (or if the patient lacked capacity, follow the decision made by the clinical team).

Is there a realistic chance that CPR could be successful?



If the clinical team is as certain as it can be that CPR would not work it is inappropriate to offer it as a treatment option.

- Allow a natural death in the event of a cardio-respiratory arrest.
- Any unexpected sudden acute deterioration must be assessed and managed as appropriate for that patient's clinical situation and goals of care.
- Good palliative care should be in place to ensure a comfortable and peaceful time for the patient with support for the relevant others.
- There should be a presumption in favour of informing the patient as part of a sensitive conversation about goals of care and available treatment options. Where the patient lacks capacity those close to them must be sensitively informed of the decision before it is documented where that is practicable and appropriate. Patients and their relevant others should be aware that they are not being asked to make a decision about CPR as it is not a treatment option, but consider whether to offer a second opinion if there is ongoing disagreement.
- Complete the DNACPR form and document the fact that CPR will not work for the patient and the reasons for this decision.
- Clearly document all discussions with the patient, relevant others and colleagues or a clear explanation of why such conversations have not taken place.
- When a patient is at home or is being discharged home they and/or their relevant others must be aware of the DNACPR form for it to be of any use in an emergency situation. If it has previously been judged potentially harmful to the patient to make them aware of the DNACPR decision this must be reviewed prior to discharge. The benefit of having the form at home may be judged to now outweigh the potential harm of the discussion about CPR in the context of end of life issues. The opportunity for sensitive discussion about this should be actively sought by suitably experienced medical and nursing staff to allow the patient to have a DNACPR form at home with them if appropriate. This information should be communicated to the senior clinician responsible for the patient in the community setting so that this information can be communicated by the Key Information Summary.
- The judgement about when and how to discuss this without causing physical or psychological harm to the patient is a matter for the patient's clinical team to decide but should always be re-considered as part of discharge planning for any patient with a DNACPR form who is being discharged home or to a care home from hospital or hospice.
- In the absence of a completed DNACPR form, it is appropriate that the medical or experienced nursing staff who know the patient do not commence CPR as long as they remain certain that CPR will fail and is therefore inappropriate for that patient.

Review at individualised clinically appropriate intervals unless it is certain that the DNACPR
decision will remain appropriate until the patient's death. Review if medical circumstances
change and if medical responsibility for the patient changes (e.g. patient discharged home
from hospital).

The original policy (2010) was adapted from the NHS Lothian Do Not Attempt Resuscitation Policy 2007, with permission of the authors Spiller J, Murray C, Short S & Halliday C, by the National DNACPR working group 2010. The policy has undergone a Light Touch Review in 2015/16 by the National DNACPR Policy Review group. Membership of the review group and the original working group can be found on the Scottish Government website http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/DNACPR.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

APPENDIX I:The DNACPR Form

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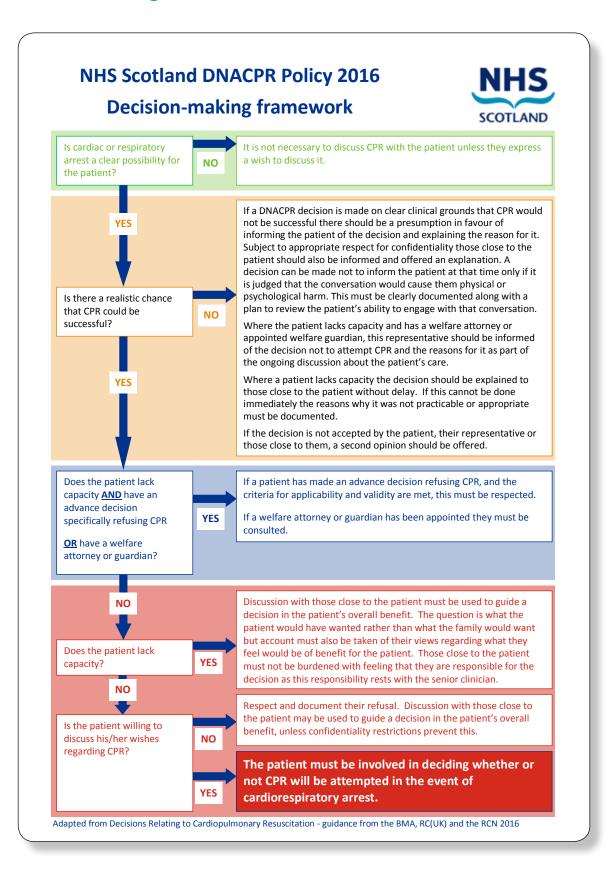
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DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)

NHSScotland DNACPR Form 08/16

APPENDIX II:

The Decision-Making Framework



A DNACPR decision is intended to prevent inappropriate attempts at CPR where it clearly will not work or would not be wanted by a patient. An inappropriate CPR attempt can cause significant harm and distress to a patient and their family as a death during, or just after a CPR attempt will be undignified and highly traumatic. A DNACPR decision does not refer to any treatment other than a CPR attempt when a patient's pulse and breathing have stopped. Any unexpected acute deterioration must be assessed and managed appropriately for that patient irrespective of a DNACPR decision, and so a medical emergency/999 call may be appropriate for a patient with a DNACPR form in place.

Clinical decisions – would CPR realistically work for your patient?

The role of the clinical team is to decide whether CPR would realistically have a medically successful outcome (sustainable breathing and circulation) – if it will not work, do not offer it. Such decisions cannot involve quality of life judgements. It may be helpful to consider whether the patient would be appropriate for care in a Critical Care or Intensive Care setting as this is the likely outcome of a "successful" prolonged CPR attempt. The overall responsibility for the clinical decision about CPR lies with the most senior clinician (doctor or nurse) who has clinical responsibility for the patient during that care period. However, agreement within the multi-disciplinary team and with the patient and their relevant others is the optimal situation.



There should be a presumption in favour of sensitively informing patients of a clinical DNACPR decision in the context of their goals of care and possible treatment options unless (i)it is judged that this conversation would cause the patient physical or psychological harm, (ii)the patient refuses discussion, or (iii)the patient lacks capacity to engage. Where harm would be caused this explanation must be documented along with a plan to review the patient's ability to have this conversation.

Patient decisions about whether CPR would be wanted

Where CPR could realistically achieve sustainable life, but the overall benefit for the patient is in question in terms of the length or quality of that life, then the patient's wishes *must be* given priority. Where a patient has capacity, clinicians cannot make a DNACPR decision based on overall benefit unless the patient makes it clear that they do not wish to engage in such a decision. It would then be reasonable to ask if there is anyone else who should be consulted.

Where a patient lacks capacity to make a decision about CPR

If a current and valid advance statement or directive exists, this should be respected. Where CPR could realistically achieve sustainable life, any legally appointed welfare attorney or guardian should be approached to be involved in the decision-making process. If no such person has been appointed then the clinical team should make a decision based on a judgement of overall benefit for the patient. Information should be sought from those who know the patient and have a view on the patient's goals, values and previously expressed wishes.

The role of the relatives / relevant others

Where a patient has capacity, their permission must be obtained before any discussion about care issues takes place. Relatives must never be given the impression that their wishes override those of the patient. Where the patient lacks capacity relatives/relevant others can give information about what they feel the patient's wishes and goals of care are, but not such that they feel burdened with this responsibility, unless their status as legally appointed welfare attorney or guardian has been established. Subject to confidentiality restrictions those close to the patient who lacks capacity must be informed of any CPR decision without delay unless it would clearly not be practicable or appropriate to do so.

Discharge to home or care home

It is the clinical team's responsibility to ensure that the patient and family are aware of the positive role of the DNACPR form at home in the context of the patient's goals of care. The family should know what to do and who to contact in the event of the patient's death or in the event of a sudden deterioration. Out of hours, the emergency care information such as DNACPR is communicated via the electronic Key Information Summary (KIS) and the GP must be given enough information to update it in time for the patient's discharge. Every effort must be made to make sure that the emergency services are not called inappropriately where a patient's death is expected, but there may be times when a 999 call is required for urgent assessment. If it is not felt appropriate or possible to have the DNACPR form at home with the patient everyone should be aware that paramedics and police may provide a full emergency response if called to attend.

Patient with a DNACPR form being transported by ambulance

Ambulance control must be informed of the existence of the DNACPR form at the time of booking an ambulance, and the crew should take the original form home with the patient, if he/she and their family is aware of it, and when not, they must understand its instruction prior to any transfer in case the patient dies on that journey.

Where no DNACPR decision has been made and a patient has a cardio-pulmonary arrest

The presumption is that staff should attempt CPR in this event, but where this is clearly inappropriate (eg a patient who is in the very final stages of a terminal illness where death is imminent and for whom CPR would clearly not work), it should not be attempted. Any healthcare professional who makes and clearly documents this considered decision must be supported by their colleagues, employers and professional bodies.

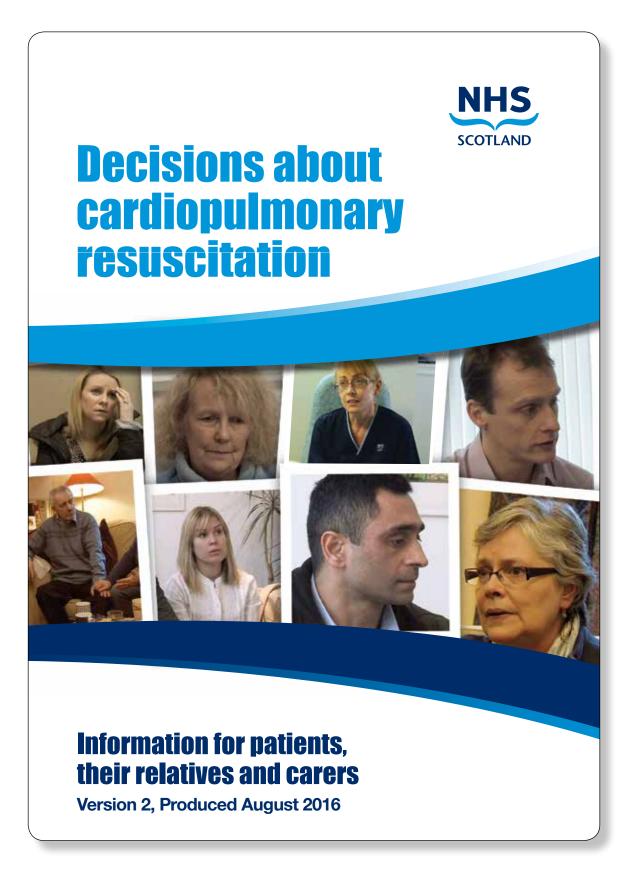
The presence or absence of a DNACPR form should not override clinical judgement about what will be of benefit to the patient in an emergency (e.g. choking, anaphylaxis).

NHS Scotland

DNACPR Framework 08/16

APPENDIX III:

Patient Information Leaflet



This leaflet is about a treatment called cardiopulmonary resuscitation (CPR). It tells you about decisions you may need to make or discuss with your healthcare team. It may also be useful for relatives, friends and carers. These conversations can be very difficult for all concerned but are so helpful in supporting people's wishes being respected.

The leaflet tells you:

- what CPR is, and
- how decisions about CPR are made

The leaflet may not answer all your questions. Please speak to your healthcare team about anything you don't understand.

What is CPR?

CPR is an emergency treatment that tries to restart your heart and breathing when they have stopped.

CPR may include:

- repeatedly pushing down firmly on your chest
- using a mask or a tube to help you breathe, and
- using electric shocks to try to restart your heart

Who will decide about CPR?

You and your healthcare team can discuss in advance if you would benefit from CPR. Your healthcare team will look at:

- your state of health
- your wishes
- whether CPR is likely to restart your heart and breathing, and for how long, and
- whether CPR will help you live longer in a way you can enjoy

If your healthcare team think CPR may work for you, they will want to know what you think. Your wishes are important in this decision.

If your healthcare team are sure CPR will not work, they can decide in advance that it should not be tried. They will write this on a form called 'Do Not Attempt Cardiopulmonary Resuscitation' (a DNACPR form). The form will be kept with your health records. A form will also be completed if a patient does not want CPR to be instigated.

You can find out what happens if you disagree with this decision in the section 'What if I want CPR, but my doctor says it will not work?' on page 6.

If your heart and breathing stop before you have had the opportunity to discuss CPR, the doctors looking after you will decide whether to try CPR. They will take account of things you have said, and how likely it is to succeed.

Is CPR likely to resuscitate me?

The chance of CPR resuscitating you will depend on:

- why your heart and breathing have stopped
- what illnesses or medical problems you have, or have had in the past, and
- your general health

Unfortunately, CPR often does not work. Your healthcare team can tell you more about this.

Does everyone get back to normal after CPR?

- Very few people make a full recovery
- People who are resuscitated will still be very unwell and need more treatment, usually in a coronary care or intensive care unit
- Most patients never get back the physical or mental health they had before they were resuscitated. Some have brain damage or go into a coma
- Patients with many medical problems are much less likely to make a full recovery

Is CPR tried on everyone whose heart and breathing stop?

- When the heart and breathing stop unexpectedly, for example if you have a serious injury or heart attack, the healthcare team will try CPR if they think there is a chance of recovery
- Your heart and breathing also stop as a natural part of dying. If you are seriously ill and near the end of your life, there may be no benefit in trying to resuscitate you when your heart and breathing stop. In

4

these cases, trying to restart your heart and breathing may do more harm than good, by not allowing you to die naturally

What if I don't want to talk about CPR?

- You don't have to talk about CPR if you don't want to
- If you feel you are not ready to talk about it just yet, you can put off this discussion
- You may wish to talk to your family, close friends or carers. They may be able to help you make a decision you are happy with
- Although this may be difficult, you should discuss CPR with your healthcare team as soon as you feel able to do it. This is to make sure your healthcare team know your wishes. It is also helpful for your family if this discussion has taken place

Who makes the decisions if I cannot decide for myself any more?

If you cannot understand the information you are given, cannot make a decision or cannot tell other people your decision, someone else may be able to say what you would have wanted.

- If you are an adult and are unable to make a decision because of your illness or a learning disability, a 'legal proxy' would be able to represent your wishes and interests in the decision-making
 - A legal proxy can be:
 - someone you appointed to be your welfare attorney before you became unable to make your own decisions, or
 - someone a court has appointed to be your welfare guardian, or

 someone a court has appointed by an intervention order to make a one-off decision about your healthcare or treatment

The doctor will always talk through the decision with the legal proxy if this is possible.

- If you don't have a legal proxy, the doctors looking after you will
 decide if you would benefit from CPR and will talk through the
 decision with those close to you if this is possible and appropriate
- Your family and friends are not allowed to decide for you, unless they are your legal proxy. But it can be helpful for your healthcare team to talk to them about your wishes. If there are people you do (or do not) want to be asked about your care, you should let your healthcare team know
- When children under 16 are unable to decide for themselves, their parent or guardian can decide for them

The Office of the Public Guardian (Scotland) gives more information about legal proxies. See page 9 for how to contact the Office of the Public Guardian.

What should I do if I know that I don't want CPR?

- If you don't want anyone to try to resuscitate you, tell your healthcare team. They must follow your wishes
- Ask your GP to add this information to your Key Information Summary. This allows your GP practice to add an electronic alert onto your medical record which can be shared with other health professionals who may be involved in your care (such as the GP out of hours service, the Scottish Ambulance Service, the Emergency Department at the hospital)

- You should let people close to you know your wishes, so they can tell your healthcare team what you want if they are asked
- You can make an advance directive (this is sometimes called a 'living will') to put your wishes in writing. If you have an advance directive, you must make sure your healthcare team know about it and put a copy of it in your health records
- It is important to know that having a DNACPR form signed does not mean that you will not receive any other types of treatments: it simply means that you will not have CPR. Other treatments may be provided according to individual need

What if I want CPR, but my doctor says it will not work?

- When you discuss CPR with your healthcare team, your doctor may tell you that CPR would not work for you
- No doctor will refuse your wish for CPR if there is a fair chance of success
- If your healthcare team is not sure CPR will work for you, they can arrange a second medical opinion if you would like one
- If CPR might restart your heart and breathing, but is likely to leave you severely ill or disabled, your opinion about whether these chances are worth taking is very important. Your healthcare team must listen to your opinions and to anybody you want involved in the discussion
- But you cannot demand treatment that will not work

If you are unhappy about the discussions you have had with your healthcare team, speak to a member of NHS staff involved in your care, if you can. If you are still unhappy and you would like to make a complaint the leaflet 'Making a complaint about the NHS' explains what to do. See page 10 for where to get a copy.

What happens when a decision not to give CPR has been made?

If you have decided you do not wish CPR to be given, or if your doctor is sure CPR will not work, this will be written on a form called 'Do Not Attempt Cardiopulmonary Resuscitation' (a DNACPR form). This will be kept with your health records and for some patients will be kept in their own home.

This decision is about CPR **only**. You will get any other treatment you need.

Your healthcare team will continue to give you the best possible care.

What if I am at home or about to be sent home?

Many patients who are dying want to know they will be able to die at home. Even if people close to you know that you do not wish CPR to be tried, they may call an ambulance in an emergency.

If the ambulance crew know you have a DNACPR form at home, they will make you comfortable but will not try CPR.

To make sure the ambulance crew know your wishes, you should:

- tell members of your healthcare team where you keep your DNACPR form, and
- tell people close to you where you keep the form

What if my situation changes?

Your healthcare team will review decisions about CPR on an individual basis. They will also do this if your condition changes or if you change your mind about your decision.

Can I see what is written about me?

Yes, you can see what's written about you. Your healthcare team will note what you say about CPR, and any decisions that are made, in your health records.

You have a legal right to see and have copies of your records, if you wish. Your healthcare team should explain any words you don't understand.

Who else can I talk to about this?

You can talk to:

- any member of staff involved in your care
- your family or friends
- your carer
- patient support organisations for example, Macmillan Cancer Support or Age Concern
- the hospital chaplain
- your own spiritual adviser, or
- independent advocacy services an advocacy service can help you express your views or make your own decisions, or can speak on your behalf

How can I find out more?

- For more information about anything in this leaflet, contact:
 - a member of NHS staff involved in your care
 - the NHS inform helpline on 0800 22 44 88
 - your local citizens advice bureau
- For more information about advocacy and to find a local advocacy group, contact:

Scottish Independent Advocacy Alliance 69a George Street, Edinburgh EH2 2JG Phone 0131 260 5380 Website <u>www.siaa.org.uk</u>

• For more information about legal proxies, contact:

The Office of the Public Guardian (Scotland)
Hadrian House, Callendar Business Park
Callendar Road, Falkirk FK1 1XR
Phone 01324 678 300
Email opg@scotcourts.gov.uk
Website www.publicguardian-scotland.gov.uk

For more information about raising a concern or making a complaint, you can get a copy of the leaflet: Your health, your rights: Feedback and Complaints from:

- GP surgeries, hospitals and other places where you receive NHS services
- www.nhsinform.co.uk/rights (alternative formats are also available here)
- the NHS inform Helpline on **0800 22 44 88**
- your local citizens advice bureau

This information was developed with Health Rights Information Scotland.

This document has been produced by the Scottish Government Health Directorates in consultation with relevant stakeholders. It is available on the Scottish Government website (http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/DNACPR). You can also ask someone in your healthcare team for a copy.





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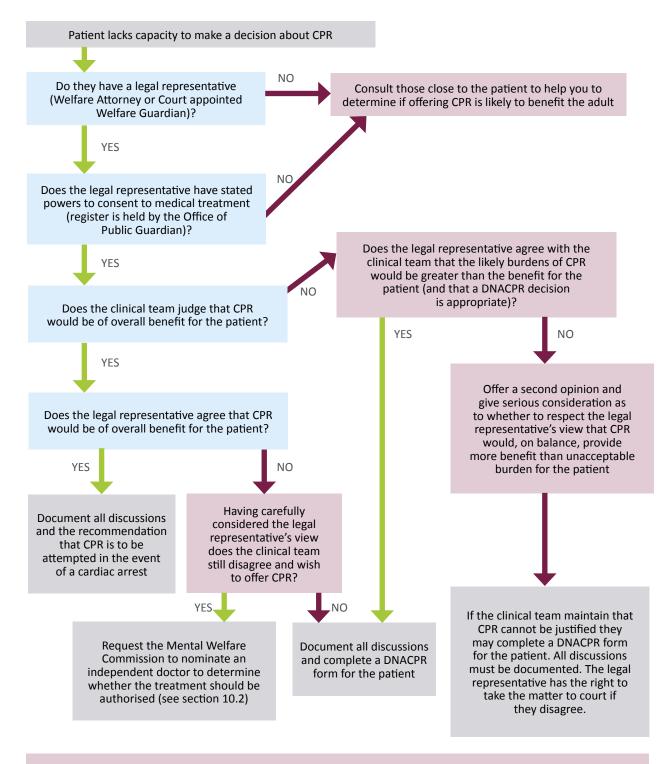
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APPENDIX IV:

Decision-making and legal representatives where CPR may be successful



In all situations, where CPR will not work it should not be offered. This decision and the reasons for it should be explained carefully to those representing and those close to the patient. Where there is objection to or disagreement with this decision, a second opinion should be offered. The court may be asked to make a declaration if it is not possible to resolve the disagreement.

Taken from; Decisions relating to CPR – guidance from the BMA, RC(UK) and RCN revised 3rd edition (2016).

APPENDIX V:

Patients with Cardiac Implantable Electronic Devices (CIEDs)

All Health Boards should have a CIED policy in place that provides guidance about the decision-making process involved in deactivation of such a device. Discussion about deactivating the CIED should take place as early as possible in the context of appropriate anticipatory end-of-life care planning for patients to avoid unnecessary distress. Prior to making a DNACPR decision for a patient with a CIED the local policy should be consulted so that an appropriate plan may be put in place.

Guidance on "CIEDs in people towards the end of life, during cardiopulmonary resuscitation and after death" is available from the Resuscitation Council (UK) the British Cardiovascular Society and the National Council for Palliative Care.

https://www.resus.org.uk/defibrillators/cardiovascular-implanted-electronic-devices/.

An information leaflet for patients and carers is also available.

GLOSSARY OF TERMS

Advance care planning

Advance care planning as a philosophy, promotes discussion in which individuals, their care providers and often those close to them, make decisions with respect to their future health or personal and practical aspects of care.

Advance statement/Statement of wishes

A written record or verbal communication on record of what the patient would wish to happen in certain circumstances. It may include changes in health state or preferences for practical things to be done in future to inform future care. Only comes into force if the patient loses capacity.*

*Scottish law does not provide a specific framework for advance statement other than for the treatment of mental illness. There is no law in Scotland that details a document or registering body for advance decisions to refuse treatment, advance directives or living wills. However, the Adults with Incapacity Act (Scotland) states that in determining what, if any, intervention is to be made, account shall be taken of past and present wishes and feelings of the adult. This guiding principle allows previous witnessed statements about an intervention to be used as evidence of previous wishes.

Advance Directive or Advance Decision**

A statement of a person's views about how they would or would not wish to be treated if the patient loses capacity. This can be a general statement about, for example, wishes regarding place of residence, religious and cultural beliefs and other personal values and preferences as well as about medical treatment and care.

**Known in England as an Advance Decision to Refuse Treatment (ADRT).

Capacity

The ability to make a specific decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make that particular decision, or communicate their wishes.

Clinician

A health professional, such as a doctor or nurse, involved in clinical practice.

End of life

Patients are "approaching the end of life: when they are likely to die within the next twelve months. This includes not only patients whose death is imminent (expected within hours or days) but those who have advanced, progressive incurable conditions; those with general frailty and co-morbidities which mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition and those with life-threatening acute conditions caused by sudden catastrophic events.

End stage

Final period or phase in the course of a progressive disease leading to a person's death.

Life-limiting condition or illness

An active and progressive condition that is expected to reduce a person's life expectancy and requires palliative care.

Legal proxy (legally appointed welfare attorney/welfare guardian/person appointed under an intervention order)

A person with legal authority to make certain decisions on behalf of another adult. The different types of legal proxy:

Powers of attorney – a means by which individuals, while they have capacity, can grant someone they trust powers to act as their continuing (financial) and/or welfare attorney in case capacity is lost at some future point.

Guardianship order (welfare and/or financial) – may be applied for by individual(s) or local authority and granted by the sheriff where the adult has lost capacity and require someone to make specific decisions on their behalf over the long term.

Intervention order (welfare and/or financial) – may be applied for by an individual or local authority and granted by the sheriff to carry out a one-off action or to deal with a specific issue on behalf of the adult with incapacity.

Overall benefit

An assessment of the appropriateness of treatment and care options that encompasses, not only the potential clinical benefits, burdens and risks of those options, but also non-clinical factors such as the patient's personal circumstances, wishes, beliefs and values. This ethical principle closely relates to the legal principles of "best interests" (England, Wales and Northern Ireland) and "benefit" (Scotland).

Palliative care

Individualised and holistic care focused on the relief of pain, distress and other debilitating symptoms of serious and life-limiting illnesses. Palliative care is not dependent on diagnosis or prognosis and can be provided at the same time as disease modifying treatment. The objective is to relieve suffering and provide patients with the best possible quality of life.

Second opinion

An independent opinion from a senior clinician who has experience of the patient's condition but who is not directly involved in the patient's care. The opinion should be based on an examination of the patient by the clinician. Exceptionally, where this is not possible for practical reasons, the clinician may give a second opinion remotely, for example by telephone, on the basis of up-to-date information about the patient's condition.

Relevant others

Anyone nominated by the patient, alongside close relatives, partners and close friends, paid or unpaid carers outside the healthcare team and independent advocates. It may, in some circumstances, include attorneys for property and financial affairs and other legal proxies such as guardians. The "named person" under the Mental Health (Care and Treatment) (Scotland) Act 2003 is also included.

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