

Review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decisions for Adults in Wales



Healthcare Inspectorate Wales (HIW) is the independent inspectorate and regulator of healthcare in Wales

Our purpose

To check that healthcare services are provided in a way which maximises the health and wellbeing of people.

Our values

We place people at the heart of what we do. We are:

- **Independent** – we are impartial, deciding what work we do and where we do it.
- **Objective** – we are reasoned, fair and evidence driven.
- **Decisive** – we make clear judgements and take action to improve poor standards and highlight the good practice we find.
- **Inclusive** – we value and encourage equality and diversity through our work.
- **Proportionate** – we are agile, and we carry out our work where it matters most.

Our goal:

- To be a trusted voice which influences and drives improvement in healthcare.

Our priorities

- We will focus on the quality of healthcare provided to people and communities as they access, use, and move between services.
- We will adapt our approach to ensure we are responsive to emerging risks to patient safety.
- We will work collaboratively to drive system and service improvement within healthcare.
- We will support and develop our workforce to enable them, and the organisation, to deliver our priorities.



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Foreword

I am pleased to be publishing this report which presents the findings from our Review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions for adults in Wales.

DNACPR decisions are an important part of end-of-life care, and during the course of our lives many of us will become involved in these discussions either on a personal level or in relation to a loved one. It is important that these discussions, and the decisions made, happen in a sensitive and effective way in order to respect the wishes and views of all of those involved. When done well, DNACPR discussions can be a positive experience, offering clarity at a time of uncertainty, ensuring that distractions are limited at such an important time.

Our work has allowed us to highlight areas of good practice, and to identify areas for improvement, which is timely with the forthcoming biennial review of the all-Wales DNACPR policy.

It is clear that understanding the patient's wishes at the end of their life is an essential element of good care and I expect health boards, trusts, and Welsh Government to carefully consider the content of this report and the overall findings from our review. I also expect health boards and trusts to consider the staff and public's feedback highlighted throughout the report, to determine how these can influence improvement with the quality of the DNACPR decision making process.

I would like to express my thanks to the staff who helped inform our review by sharing information, participating in our interviews and focus groups, and for completing our surveys. In addition, to Professor Mark Taubert for his continuous support and professional advice throughout, and finally to those who supported us by completing our public survey.

To close, I must take this opportunity to pay tribute to the staff who take part in discussions about DNACPR decisions, and to those who provide care and support to people at the end of their lives. The compassion and dedication of those we engaged with throughout this work is heartening and provides a strong and positive basis upon which to improve.

Alun Jones
Chief Executive
Healthcare Inspectorate Wales



Summary

The review explored whether patients are actively involved in decision making about DNACPR and whether those decisions are clearly recorded and communicated between healthcare professionals.

It is clear from our review's findings that there are examples of noteworthy practice across Wales regarding the DNACPR decision making process. However, we have also identified opportunities to improve. These include the need to strengthen the quality of communication with both patients and those close to them, and across different healthcare teams. This is to ensure that discussions and DNACPR decisions and the rationale behind these, are clearly recorded and communicated between healthcare teams.

[Cardiopulmonary Resuscitation \(CPR\)](#) can in theory, be attempted on any person when their heart and their lungs cease to function. The joint guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing; [Decisions Relating to Cardiopulmonary Resuscitation](#), highlights that clinical outcomes following CPR are dependent on the clinical factors that led to the situation. Unfortunately, in many instances, the CPR procedure does not always result in a good clinical outcome, and when people do survive, there is significant risk of harm and long-term complications.

When people are affected by life-limiting and palliative illnesses, an open discussion about the reasons not to resuscitate them if their heart and lungs cease to function, can be an important part of advance care planning, and can help minimise distress at a later stage. To facilitate and support the DNACPR decision process, clinicians in Wales who make decisions not to resuscitate a person, must legibly and fully complete a DNACPR Form. This will ensure that the patient's wishes are respected and that decisions reflect the best interests of an individual. This is highlighted within the [all-Wales DNACPR Policy](#).

A key area and focal point during our review, and one where improvement is required, is the need for accurate and effective recording on DNACPR forms. Our review has highlighted that across Wales, the legible and full completion of DNACPR forms and the supporting or additional written accounts within an individual's clinical records was variable. Illegible or incomplete records can have a negative impact on effective communication across healthcare teams about a DNACPR decision.

We reviewed approximately 280 DNACPR forms during our work. It was positive to find some good examples of concise and thorough explanations of patient

discussions, and instances where a clear indication had been given for any absence of discussion with patients and/or those close to them. We also found examples of comprehensive narratives written within patient clinical records to support the DNACPR form. However, improvements are needed in the way that information is recorded on the forms to support communication of the DNACPR decision.

A central element that is critical to making DNACPR decisions is communication. There is room for improvement to ensure that people's experience of DNACPR discussions is as informative and holistic as possible. Most staff who we engaged with felt that individualised communication is at the centre of all DNACPR decision making, and that this is done in an open and honest way. However, we found that this could be strengthened further, by having DNACPR discussion with patients at an earlier point during their illness, instead of these taking place closer to the end of their life. This is crucial in enabling people to feel informed and understand what will or will not happen once the decision not to resuscitate is made.

Understanding the patient's wishes at the end of their life is a fundamental element of good care. We feel more can be done to improve people's awareness of DNACPR and access to information resources, to help them come to terms with and understand the DNACPR decision process. Whilst our review identified that resources are available to support this, it was disappointing to find that three quarters of respondents to our public survey said they were not provided with supporting information about the decision not to resuscitate.

Whilst a third of respondents to our public survey felt they were aware of what a DNACPR decision meant, prior to discussing this with clinicians, over half felt their understanding did not change following a DNACPR discussion. However, we received some positive examples where patients said they had received ongoing care and active cancer treatment, and the DNACPR decision did not mean this would discontinue, as they originally thought.

It is therefore evident that improvement is needed to support the public's understanding of the DNACPR decision making process, and its implications for individuals receiving care and support for their ongoing health needs. A DNACPR decision does not mean an immediate end to patient care and support, rather it means the individual will not be resuscitated in the event of cardiac arrest or dying naturally, because of deterioration in their existing clinical condition.

It was disappointing to find that almost half the respondents in our public survey felt their accessibility needs were not considered during DNACPR discussions, with most saying that their communication needs or preferences were not discussed. However, we also heard positive comments from people about the resources which helped their understanding, such as videos and leaflets. These included, [“Sharing and Involving”- Information for patients and their carers to help make decisions](#)

[about CPR](#), and online resources, such as [Talk CPR - Discuss DNACPR](#), and the dedicated YouTube Channel [Byw Nawr - Live Now](#).

A key issue to have emerged from our review relates to patients having the mental capacity to make and communicate decisions about CPR, and the quality of how these details were recorded on the DNACPR form. Whilst this section of the form was generally well-completed for people who had capacity, this was not always the case for those who may have lacked capacity. We found some forms and clinical records either contradicted each other, were incomplete, or there was no evidence that a mental capacity assessment had been undertaken and without rationale. We are therefore not assured, based on the records we reviewed, that the DNACPR decision making process is always completed in line with the all-Wales Policy, for patients who were deemed to lack capacity. This issue must be addressed by health boards and trusts.

Training and support for staff around DNACPR discussions and decision making, emerged as a consistent theme through our review. Training modules, resources, and information to support clinicians is available nationally. However, a recurring issue appears to be staff awareness of these resources and their ability to access them in a timely manner. These resources are valuable and can help ensure that DNACPR discussions can be held in a person-centred way, that meet the needs of people. For instance, it can be challenging to hold conversations with people about DNACPR when communicating with those who have strong beliefs, for instance cultural or religious, or with people who have learning disabilities. Only 40% of staff survey respondents said their organisation provides appropriate equality and diversity training or support, which contradicted information provided to us by each organisation.

It was positive to find that communication aids for people with language barriers and sensory or cognitive impairments are widely available across Wales. Access to interpretation and translation services is also available and includes support for those with hearing and sight impairments. However, once again we heard that staff were not always aware of the resources available to support them when having discussions with people who have communication challenges.

The general disparity regarding staff training may in part be due to constraints on the ability of staff to attend, or a lack of awareness of its availability. Irrespective, we believe more should be done to ensure staff can access the resources available to them to support effective DNACPR conversations.

We found the summaries of main clinical conditions and reasons why CPR would be inappropriate were generally well-completed on the DNACPR forms. However, the form's free text box has minimal space for a clinician to record all relevant information. On a practical level, staff felt that expanding the size of the free text

box on the form would aid with capturing the more pertinent points more effectively. Whilst we saw some positive examples of concise and thorough summaries of patient clinical conditions, and clear indications why CPR would be inappropriate, we also saw other summaries which were sparse or illegible. We therefore concluded that documentation in the clinical condition section of the form must be strengthened, to help ensure there is no ambiguity or misinterpretation of what is recorded.

It was concerning to find that almost a third of staff responding to our survey, felt that communication across healthcare teams about DNACPR was not at all effective. A theme arising from our survey was the need for effective information sharing across healthcare teams, with particular reference to the need for an all-Wales electronic repository for the DNACPR form. The benefits of an electronic system would enable people and services, such as patients, clinicians, GP practices, out-of-hours services, WAST staff and the NHS 111 service, to access a central system promptly, to establish if a patient has a DNACPR decision in place.

Whilst an electronic repository would not eradicate all risks and challenges, as it would still be reliant upon its effective usage by staff, such a system may be beneficial in bridging the gap between hospital, community and primary care settings, or from one health board to another. Such a system could help to support the efficient sharing of crucial information around DNACPR.

It is clear, that lessons can be learned from both the staff and public's experience and feedback of DNACPR decision-making as highlighted throughout this report. Health boards and trusts should consider these views and identify how they could influence improvement around the quality of the DNACPR decision process, and the experience of patients and those close to them.

It is important to highlight that the staff we engaged with during interviews, focus groups, and through the responses received in our staff survey, endeavour to support people with the dignity and respect they deserve during the end of a person's life. We have found that there are positive examples where DNACPR discussions take place well, and in a timely manner before the end of someone's life. However, these can be challenging and distressful times for those involved, and sometimes there is little time available for thorough discussions, particularly during unforeseen emergency situations.

Overall, we found examples of noteworthy practice, but also areas needing improvement. Health boards and trusts must consider the findings of our review and act on our recommendations to drive improvement in relation to the DNACPR process. This includes the need to reflect on the experiences of staff and the public, which are highlighted throughout the report.

We would like to express our thanks to the staff who helped inform our review by sharing information, participating in our interviews and focus groups, and for completing our surveys. In addition, we are thankful to Professor Mark Taubert for his continuous support and professional advice throughout our review, which was appreciatively received. Finally, we wish to thank those who supported our work by completing our public survey.

Context

With the unprecedented demand on the healthcare system worldwide during the COVID-19 pandemic, there was a significant increase of patients being admitted to hospital with the virus. The pandemic drew into focus and highlighted concerns about conversations on what Cardiopulmonary Resuscitation (CPR) involves, and its success rates for those with COVID-19.

In April 2020, Welsh Government was alerted to concerns from advocates of disabled and learning disability communities. This related to the [Clinical Frailty Scale](#) being used inappropriately at times, when making clinical decisions on escalation of care, ceilings of treatment and DNACPR, for individuals positive with COVID-19. Subsequently, the Chief Medical and Nursing officers for Wales issued a joint letter across NHS Wales, highlighting the implementation of a framework of values and principles for healthcare delivery in Wales, to support services when making decisions during the pandemic.

The framework addressed the importance of openness and transparency to those with professional and legal responsibilities when making DNACPR decisions. It also highlights the existing all-Wales DNACPR policy; [Sharing and Involving - a clinical policy for Do Not Attempt Cardiopulmonary Resuscitation \(DNACPR\) for adults in Wales](#), relating to the 'the duty to consult' patients, and those close to them, when clinicians are making decisions about DNACPR.

The report, [Protect, Respect, Connect - Decisions about Living and Dying Well During COVID-19](#), was also published by the [Care Quality Commission \(CQC\)](#) in March 2021. It was commissioned by the UK Government in response to media stories, complaints, and campaigns about perceived failings with DNACPR decisions in NHS England. The report's outcomes acknowledged that the extreme demands of the pandemic response had increased pressure on health and care staff which may have hampered decisions, and specifically communication around DNACPR. In addition, that DNACPR decisions do not exist in isolation but are part of a broader spectrum of care planning for long term conditions, advance care planning for end-of-life decisions, and emergency treatment escalation plans. Furthermore, there was clear acknowledgment from CQC that clinicians should be doing more of all these things.

What We Did

In response to the national concerns highlighted in the context section, and key intelligence held by HIW, we wanted to understand more about DNACPR decisions in Wales and decided to commence a review. In January 2023, we commenced the scoping of our work and engaged with a sample of NHS Wales services and the public, to help inform and refine the review. We paused our work to explore and consider other projects being undertaken across Wales in relation to DNACPR, then recommenced our review in September 2023.

We wanted to consider the practices in place when DNACPR decisions are applied to adults (over the age of 18), and whether patient views and considerations are respected. We explored whether DNACPR decisions reflect the priorities of an individual, including their preferred requirements, and whether a DNACPR decision was clearly recorded and communicated between healthcare teams, and to the patient and those close to them.

The key question that we have sought to answer is whether DNACPR decisions are being respectfully communicated to patients and those close to them, and are they clearly recorded and communicated between healthcare professionals?

Scope and Methodology

We requested key documents and information from all health boards and Velindre University NHS Trust (Velindre). We also considered documents and information shared with us by the Welsh Ambulance Services NHS Trust (WAST).

The review considered:

- DNACPR forms submitted to HIW by health boards and Velindre (remotely)
- DNACPR forms and accompanying clinical records at two health boards (onsite)
- Organisational policies and procedures for DNACPR decisions
- Organisational processes for auditing DNACPR decision making
- How healthcare staff maintain their knowledge and skills in communication with people in relation to DNACPR.

Staff Engagement

We engaged with healthcare staff through interviews and focus groups to provide them with the opportunity to discuss the DNACPR processes in place in their organisation. We also launched a staff survey to gain an understanding of their experience and perception of their organisation's DNACPR processes. This was

circulated to staff via health boards, and was promoted through our stakeholders, [our website](#) and our social media channels.

We received 65 responses to the survey, some were partially completed, however, all were considered during the review. Most respondents (59%) worked in secondary care settings, and 'others' were from hospice care, research teams, WAST and community and primary care settings. Our findings on staff engagement will be highlighted throughout the report.

Public survey

We launched a public survey to seek peoples' experience relating to DNACPR, and whether decisions were respectfully communicated to patients and those close to them. The survey was available online, in hardcopy, and people could complete the survey over the telephone with a member of the review team, and our stakeholders also helped share the survey.

We received 32 responses, some were partially completed, however, all were considered during the review. The greatest response came from relatives and carers, who represented 75% of respondents, 14% from those with [lasting power of attorney](#), 6% stated they were 'other' and 5% from patients. Our public survey findings will be highlighted throughout the report.

Fieldwork

Most of our fieldwork was completed remotely, supplemented by onsite visits at two health boards, namely 'Aneurin Bevan' and 'Hywel Dda' University Health Boards. These health boards were selected having considered information provided to us during our scoping phase in early 2023, the intelligence held by HIW, and the age demographics of individuals aged 65 and over for each health board area as published by [Stats Wales](#). We attended Aneurin Bevan during November 2023, and Hywel Dda during December 2023, where we reviewed DNACPR forms alongside the relevant clinical records and considered the completeness and quality of documentation. In total, we reviewed 66 DNACPR forms in depth, alongside the relevant clinical records.

Review team

Our review team consisted of:

- HIW Senior Healthcare Inspector (who led the review)
- HIW Healthcare Inspector (who supported the lead and review team)
- Two Clinical Peer Reviewers with significant expertise in both acute and long-term clinical patient care

Clinical guidance for DNACPR in NHS Wales

In considering the effectiveness of processes relating to DNACPR decision making, we looked at whether health boards and trusts comply with the [all-Wales DNACPR](#)

Policy. This policy was launched in February 2015 and was revised and updated in 2017, 2020 and 2022, and will be reviewed every two years. Throughout this report, we refer to this as the ‘all-Wales Policy’. It acts as a form of ‘highway code’ for best practice decision making when it comes to naturally anticipated and accepted deaths, where a DNACPR conversation and decision should be considered.

What We Found

The all-Wales DNACPR Policy

The [all-Wales DNACPR Policy](#) provides the framework for clinicians in Wales to help ensure a uniformed approach to decision making about the provision of CPR at the end of life. It also aims to raise awareness of the importance of discussions that relate to peoples' wishes at the end of their life. The framework helps ensure that a patient's wishes are respected, that decisions reflect the best interests of an individual, and benefits are not outweighed by burdens, and that a DNACPR decision is clearly recorded and communicated between clinicians.

The policy reflects that CPR, in theory, can be attempted on any person when their heart and their lungs cease to function. However, as highlighted in the publication; [Decisions Relating to Cardiopulmonary Resuscitation](#), clinical outcome is dependent on a person's clinical factors that led to the situation, and the policy outlines that in many instances, CPR does not result in a good clinical outcome. When people do survive, there is significant risk of harm and ongoing patient complications. The policy highlights that undertaking CPR may not be appropriate for all people, and therefore stipulates that a decision not to attempt CPR should be reached, based on a proper and appropriately informed discussion with patients, whilst involving those close to them.

The policy sets out the requirements for the clinician completing the DNACPR Form (Adult) Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) discussion. A copy of the form can be found below; this is for reference as we will refer to sections of the form throughout the report. The form can also be found within the all-Wales DNACPR Policy.

Copy of the all-Wales DNACPR Form (Adult):

DNACPR Form (Adult) DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) DISCUSSION			
Date of DNACPR Discussion:	/ /	Surname:	
Date(s) Reviewed	/ /	First Name:	
Reviewed by		NHS/Hospital No:	
(Signature/Reg. No)		Date of Birth:	
		Home Address:	
THIS FORM <u>MUST</u> BE FILED AT THE FRONT OF THE PATIENT'S HEALTHCARE RECORD			
1. Does the patient have capacity to make and communicate decisions about CPR?		YES / NO	
If "NO"			
Are you aware of a valid Advance Decision to Refuse Treatment (ADRT) refusing CPR which is relevant to the current condition? If Yes, please append a copy		YES / NO	
Has the patient appointed a Health & Welfare Attorney to make decisions on their behalf?		YES / NO	
If "YES" they must be consulted.			
2. Summary of the <u>main</u> clinical conditions and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests			
Clinical Summary (must be filled in)			
Select reasons that apply to this individual situation:			
Not in the best interest/harm from CPR > benefit		☐	
Patient refused CPR		☐	
This is a natural anticipated and accepted death		☐	
Other (please elaborate in patient's healthcare record)		☐	
3. Has a discussion taken place with the patient?		YES / NO	
Please summarise decision below. If <u>NOT</u> discussed, please <u>record reasons, incl potential for harm from discussion</u> :			
Summary (must be filled in):			
4. Has appropriate discussion taken place with those close to the patient, a Health and Welfare Attorney or an IMCA? Please also record unsuccessful attempts to contact them in text box.		YES / NO	
Name of person:		Relationship to patient:	
Summary (must be filled in):			
5. Healthcare Professional completing this form (must inform Senior Responsible Clinician):			
Name (PRINT):		Position:	
Contact Details:		GMC No: NMC/HCPC No:	
Signature:		Date:/...../..... Time:	
6. Senior Responsible Clinician with oversight to sign below: (Must inform MDT/others involved in the care of the patient of the decision – record the communication in section 8)			
Name (PRINT):		Position:	
Contact Details:		GMC/NMC No:	
Signature:		Date:/...../..... Time:	
7. CANCELLATION of decision: NB: Cross form CLEARLY and write "CANCELLED" across form – notify ALL copy holders (see details below)			
Name (PRINT):		Position:	
Contact Details:		GMC/NMC No:	
Signature:		Date:/...../..... Time:	
8. COPIES of this DNACPR decision form have been sent to:			
1.	☐	Patient /Carer	
2.	☐	GP/Consultants involved	
3.	☐	Care Home	
4.	☐	Out-of-hours providers	

The DNACPR form is used to advise clinicians not to attempt CPR when death occurs, due to the stated medical reasons on the form, such as a person with lung cancer, with spread to other part of the body. Therefore, denoting a life limiting incurable condition as highlighted in the publication, 'Decisions Relating to Cardiopulmonary Resuscitation' highlighted earlier. The DNACPR form is designed to be easily recognised and swiftly verifiable on one page, thereby allowing clinicians to make quick treatment decisions in both hospital and community settings about starting CPR. These are often split-second decisions, so a form must be brief and to the point.

The form also aids communication between patients, relatives, and all clinicians in scenarios where CPR should not be attempted. Without a form in place, it is likely that full CPR may be attempted against the patient's wishes. The [General Medical Council \(GMC\)](#) and [Nursing and Midwifery Council \(NMC\)](#) clearly state that where appropriate, clinicians can make a clinical decision not to administer CPR, even if no form is in place, and that this must be an individualised decision.

The DNACPR form was revised in July 2023 following publication of the '[All Wales Competency Framework for Completion of the all-Wales DNACPR form \(Section 5\) by Registered Health Care Professionals \(HCPs\)](#)'. This framework was implemented to support the appropriate registered HCPs, such as Advanced Paramedic Practitioners, to undertake the required training and demonstrate key competencies, to allow them to hold DNACPR discussions and to make decisions about commencing CPR. During our staff focus groups within Hywel Dda, we also found that some community based Advanced Nurse Practitioners have also undertaken training to enable them to complete section 5.

Regardless of which clinician completes a DNACPR form, the all-Wales Policy states that all sections must be legibly completed and must contain up-to-date clinical information. Once complete, the form can be used anywhere, for example, in a person's home, in hospitals, hospices, care homes, and during ambulance journeys.

Date of DNACPR discussion and patient identification

The initial section to be completed on the form contains the dates of any DNACPR discussion (and review dates), and patient identification details. During our remote review of the DNACPR forms, we were unable to review the patient details as these had been appropriately redacted by the organisations prior to submission to HIW.

We found the date of discussions was completed on most forms, however, the review dates, the signature of reviewing clinician and their GMC registration numbers were sometimes incomplete. A review date omission may be due to a patient's status not requiring a review. However, for those that were completed,

several GMC registration numbers were illegible, although, it was positive to note that within some, an ink stamp with the GMC number was inserted.

Recommendation 1:

Health boards and trusts should ensure that clinicians completing the date section ‘for review’ within a DNACPR form, must clearly document all the required information including the date and their professional registration numbers, to ensure that clinicians are identifiable if required.

When reviewing DNACPR forms and clinical records onsite within Aneurin Bevan, we had concerns which needed immediate attention around documentation in general and the filing and storage of clinical records. We wrote to the health board outlining our concerns in line with our immediate assurance process. The health board responded with an improvement plan demonstrating how it will address our concerns, which has since been accepted. We will continue to monitor the progress of improvements and their sustainability, through our reviews follow-up process. We will refer to our concerns where applicable throughout the report.

Are DNACPR decisions being respectfully communicated to patients and those close to them?

We have chosen to divide the review’s main question into two parts and will initially focus upon the patient experience, and effectiveness and quality of the communication of DNACPR decisions to patients and those close to them. In considering this question, we will draw from our analysis of the relevant sections of the DNACPR form and the findings from our fieldwork and public and staff surveys.

Has a discussion taken place with the patient?

The all-Wales Policy highlights that in most cases a DNACPR decision should be made after a carefully planned discussion in partnership with the patient, and should involve those close to them, if the patient agrees. The policy highlights that decisions relating to DNACPR must be accorded a high level of prominence, to ensure discussions are allocated sufficient time, and peoples’ views are explored. Clinicians must state clearly what was discussed and agreed with the patient, and if the DNACPR decision was not discussed, the reason should be documented.

In our review of section 3 on the DNACPR form, it was positive to find good examples of concise and thorough explanations of patient discussions during our remote review, and clear indications for any absence of discussions. However, we found some examples needing improvement, where free text sections had not

been completed at all. We were not able to cross-check this within the clinical records since we did not have access to these remotely, so they may have contained detail on discussions within them. We acknowledge this may be considered a limitation in our review; however, we can appropriately report our findings relating to our remote review of the forms we received during our scoping of the work.

During our onsite fieldwork, we found some examples of positive practice. This included comprehensive narratives within clinical records and clear summaries of patient discussions or with those close to them. For example, detailed discussions about the risks and benefits of CPR and the DNACPR process to fully inform the patient in making a DNACPR decision. However, we found one example following a patient admission to the Emergency Department, where documentation said "DNACPR in community, brought copy in". However, there was no evidence of the DNACPR form within the clinical records, which meant it was not clear whether a patient discussion had been appropriately held. We found another example where a most recent copy of a completed DNACPR form had no details of a patient discussion.

We acknowledge that the free text box within section 3 is limited, therefore, clinicians should be succinct, with further narrative about patient discussions captured in clinical records. Ensuring the succinct recording of patient discussions on the DNACPR forms is pivotal in supporting lines of communication across healthcare teams, without needing to further explore this in the relevant clinical records.

Has an appropriate discussion taken place with those close to the patient, a Health and Welfare Attorney or an Independent Mental Capacity Advocate (IMCA)?

If the patient does not have mental capacity, then those close to them must be consulted, and may be able to support the discussion by indicating the patient's recent wishes. Their name and relationship to the patient should be recorded on the DNACPR form. They should not be asked to make the decision to withhold CPR, which is a clinical decision, but should share what the patient's views and wishes are regarding CPR. If the patient has appointed a [Lasting Power of Attorney](#) (LPA) for health and welfare to make decisions on their behalf, that person must be consulted.

Our remote and onsite findings for section 4 were variable. We found good examples of clear information on some forms, and some examples where attempts were made to contact a named patient advocate or LPA, which was supported by clear documentation. We also found a clearly documented example where a patient had expressed their wish for the family not to be consulted about their

DNACPR decision, which is an important consideration for clinicians. However, we found some examples where section 4 had not been completed at all. Some forms had brief details, such as ‘*a broad discussion with relatives had taken place with patient present*’, and another stating ‘*the patient was drowsy*’, with no evidence that further attempts to hold discussion with them, or with their relatives.

During our fieldwork in Aneurin Bevan, we were not assured that all staff were maintaining an appropriate standard of documentation following DNACPR discussions, which could impact on communication across relevant teams. We addressed this issue with the health board through our immediate assurance process as highlighted earlier.

Staff experiences of discussions for DNACPR decisions

Our staff survey highlighted a mixed response about the quality of DNACPR discussions with patients. Over 50% felt they provided information and clarity for patients to understand a DNACPR decision, however, very few felt that sufficient time was available for patients to make an informed decision. One comment included:

“The discussion regarding DNACPR is left too late and needs to have a higher priority within a patient’s illness. Even if there is not completion of the form per se there should be dedicated time in a patient’s care, to introduce the concepts of DNACPR and advance care planning”.

This comment resonates with National Institute for Clinical Excellence’s [Quality Standard 13, End of Life Care for Adults](#). It highlights ‘adults approaching the end of their life should have opportunities to discuss advance care planning’ to provide the opportunity to have meaningful, person-led discussions, that allow people to make decisions and plans for their future care while they have the capacity to do so.

We also found positive examples through our engagement with staff about them holding open and honest discussions. This included, giving people opportunities to discuss the decisions, and provide them with emotional support. Staff also elaborated and empathised at how difficult these conversations are. 68% felt individualised communication is at the centre of all DNACPR decision making. This was supported by comments highlighting good practice, and suggestions for improvement, which included:

“Some clinicians have a very good way of explaining what DNACPR is and what that means. It’s always inspiring to see a good DNACPR discussion. Guidance on how to approach the conversation using scenarios would be helpful. I am always impressed at how the palliative care team approach the conversations”.

In relation to improving the DNACPR decision process within their organisations, comments included the need to facilitate earlier patient discussions about DNACPR, and that nursing staff could begin having conversations with patients if supported by relevant training. 45% of staff felt that the documentation does not always suitably capture the full communication with patients and those close to them about DNACPR. One staff commented:

“Whenever I have had a DNACPR conversation, I have found that the comments box is too small to document fully what was said and with whom”.

We also received a comment highlighting issues with accessing evidence of a DNACPR discussion held with the patient and family within clinical records, during previous hospital admissions. It was felt that additional documentation about discussions is not always added or attached to the DNACPR form, and attempting to find this within previous clinical records can be a challenge. Other comments included:

“...although the amount of narrative sometimes varies depending on who completes it. I like to put some detail about what was discussed and the pts priorities and goals regarding ceilings of treatment/ end of life care in relation to CPR”.

The space within the free text box for sections 3 and 4 is limited, and it is not always possible to capture details of a full discussion in either box. However, as highlighted earlier, the policy states the expectation that a clinician should capture key elements on the form and provide further detail within the clinical records (which can be referenced on the form against a specific date, for ease of finding it later).

Patient understanding of DNACPR decisions

In the publication by Marie Curie Palliative Care Research Centre in Cardiff University, following its large national survey on [Public Attitudes to Death and Dying in Wales](#), it was reported that 92% of the 8077 UK respondents (total of 4215 people participating from Wales), think it is important to express future health and care preferences in advance of serious illness and dying. It is, therefore, fundamental that patients and their nominated proxy understand that a DNACPR decision is about addressing attempted full CPR in the event of cardiac arrest or natural dying and does not mean that patients will not receive the required care and treatment prior to that event.

Regardless of when a DNACPR decision is made, patients should continue to have the relevant care, treatment and support they need, up to the point of death. People must also be given the chance to understand how the DNACPR decision is made, and why CPR may not be suitable for them. The patient’s wishes and

preferences should always be considered; however, it is important to note that the clinician, can and will, make the final decision around resuscitation.

To support the patient understanding of a DNACPR decision, further conversations should provide additional clarification once they have had the time to reflect on the decision made. We considered staff evaluation of the patients' understanding in our survey. 71% felt that clarity is always provided to support the patient's understanding that a DNACPR decision relates to active full CPR and does not mean withholding other forms of care or treatment prior to cardiac arrest or natural dying. We found several staff comments highlighting how they seek assurance that patients and families understand what was said during the DNACPR discussion, which include the following:

"I usually go back and check with patients and families [regarding] their understanding if I have had the conversation, or if it has happened recently with another professional. Also, if patients are admitted from community with an existing DNACPR on their electronic record, I recheck their understanding and awareness of this".

"It is always reassuring when appropriate questions are asked following the discussion, indicating that they have followed and understood the information given".

We also considered the public's understanding of DNACPR. Although the response rate was low to the public survey, of those who responded, 60% felt that the clinician did not adequately answer their questions, and 67% felt that there was not enough information provided, and time, to make an informed decision.

We also enquired whether people understood the meaning of DNACPR decisions prior to discussing this with a clinician, and the responses varied. Over 30% felt they were aware of what the decision meant prior to the discussion, whilst others said they did not know much about the topic, or their understanding was to agree the "correct course of action". Some examples include:

"We thought it was to allow doctors instead of the patient and/or a family member to make the decision not to resuscitate".

"That they would not be revived. That their illness [and] age was a factor in the decision making".

"To inform medical professionals of the patient's wishes not to carry out an intrusive process if their heart should stop".

Some patient resources in Wales describe in detail, what can be the brutal process of full CPR at the point of dying. We therefore asked people in our survey whether their understanding of DNACPR changed following the discussion with a clinician.

55% felt their understanding did not change following a discussion, and when asked to expand on their answer, one comment included:

“It was made clear it was a medical decision and patient/family views were not considered in making that decision. It was also NOT made clear that there were no medical concerns at the time about its likely need, just that it was being spoken about as ‘best practice’ on admission to an acute medical ward”.

Some people better understood what the DNACPR decision meant following their conversation with a clinician. One comment reflected their understanding had changed, and their treatment had continued following the DNACPR decision. They had received full cancer treatment since the discussion was held, and the DNACPR decision had not changed their treatment plan. This response highlights the importance of ensuring that clinicians provide patients and relatives with sufficient information and clarity, to ensure people can have a fully informed discussion to understand and make a DNACPR decision.

We asked people in our public survey whether there was anything they found particularly helpful or could be improved upon in their experience of the DNACPR discussion. The main theme arising from comments, was that an improvement in clinician attitudes could be made during the discussion around DNACPR. Some comments reflected their experiences as:

“More respect, empathy required. Especially when a patient has difficulty understanding even the most basic information. Should be discussed at an appropriate time NOT when you are distressed and in pain”.

“How it was delivered (as it sounded very flippant). Who was there and consulted on about it. The vulnerability of the patient needs to be [considered] before having the conversation”.

Sadly, this resonates with some of the findings highlighted in the report; [What People Need from a DNACPR Decision and Discussion](#), where people described their accounts of poor experiences during DNACPR discussions.

We did receive comments of a more positive experience which reflected:

“Good to talk through with the nurse who explained it all. Very clear communication. Then talked to a doctor. Was given form to take home and given to my son, too”.

We also asked the public whether there was anything further they would like to tell us about their experience of a DNACPR discussion. The comments were mixed, with some reflecting discussions which took place over the telephone. Whilst we cannot confirm the reason for this, we must acknowledge that this may have occurred during the height of the COVID-19 pandemic, when the healthcare system’s response to the pandemic and national lockdown meant that a family

member was not allowed to visit the hospital. Therefore, clinicians had no other option than to discuss this over the telephone. Some comments included:

“The phone call came out of the blue - it just upset my mother greatly. I feel this discussion should always be done face to face unless the persons involved are fully aware of the conversation which will be taking place”.

“It would be more appropriate to discuss with a loved one NOT, I repeat, NOT leave a voicemail”.

The above highlights the difficulty in finding the balance between the duty to consult and inform, versus the need to sensitively convey this information, ideally at the next face-to-face visit (if relatives are allowed to visit). We also found that resources were shared with NHS staff by the Wales Cancer Alliance on [how to break bad news remotely via video-calls and telephone](#). This helped support staff during covid with remote discussions about DNACPR. Additionally, it is still a relevant resource if required to undertake remote discussion in the future. In most situations, such conversations take place face-to-face.

In our public survey, we asked questions which considered the quality of the DNACPR discussion. It was disappointing to find over 51% felt they were not treated with dignity and respect, and 57% felt they were not listened to. In addition, 60% felt they were not as involved in the decision as they wanted to be, and that the role of the clinicians within the DNACPR decision process, was not explained clearly to them.

Patient information supporting DNACPR decisions

The all-Wales Policy highlights that patients and those close to them should have the opportunity to further explore their understanding of DNACPR, and how successful or unsuccessful a CPR attempt may be. The policy highlights that people should be offered resources to support their understanding. Examples of these include:

- The [‘Sharing and Involving’ Information for patients and their carers to help make decisions about CPR \(Cardiopulmonary Resuscitation\)](#)
- Online resources, such as [Talk CPR - Discuss DNACPR](#)
- The dedicated YouTube Channel [Byw Nawr - Live Now](#)

The Older People’s Commissioner for Wales also provides resources to people which can be accessed on the website; [‘Understanding DNACPR’: Information and Advice about Do Not Attempt Cardiopulmonary Resuscitation Decisions](#).

Supporting information can help a person reflect on discussions or help develop their understanding about CPR and DNACPR decisions. In our public survey, we

asked people if they felt sufficiently informed regarding their DNACPR decision; 76% felt that no informative resources were shared with them about DNACPR. For those who did receive information, some said they were provided with resources, such as leaflets and links to the Talk CPR online resource.

Through analysis of the pre-fieldwork information sent to us by health boards and trusts, we found both staff and patient resources are available for staff to access on health board or trust intranet sites. The intranet sites also provide links to additional resources external to an organisation. We discussed information resources with staff in our focus groups, and it was highlighted that many patient resources are electronic, therefore, it can be a challenge to access for some people who cannot use electronic resources. It was also felt that further consideration should be given to the accessibility of offline resources. We also received comments relating to patient information in our staff surveys, which included:

“Sharing and involving booklets routinely offered. DNACPR conversations can take [several] conversations - patients/ [next of kin] given time to process information when needed. Joint conversations with oncology and palliative care teams can be effective for complex decisions/discussions”.

“Proper promotion of what DNACPR means. Information leaflets that patients can go home and read. Early discussion so that patients aren't shocked by the discussion”.

Whilst there are several resources available which people can access about DNACPR, our review has found that improvements should be made to ensure people can easily access this information.

Recommendation 2:

Health boards and trusts should ensure that clinicians are providing or signposting patients and those close to them with sufficient information resources, in an appropriate format, to help them understand and consider the CPR process, and what DNACPR means.

Recommendation 3:

The Advance and Future Care Planning Group (Wales) should consider how to further increase public awareness within health boards and trusts regarding the existing resources and the meaning and process for DNACPR decision making, to ensure people can appropriately engage in conversations about their preferences during the end of their lives.

Quality of Staff/Patient discussions around DNACPR

During our staff focus group at Hywel Dda, we heard examples of staff taking a holistic approach to DNACPR discussions, with some occurring over several days or

weeks. For example, nurses often have an opportunity to get to know the patient whilst providing care in hospital or the community and discuss with patients and their family their thoughts and feelings around resuscitation. It was explained that these conversations are empathetic and sensitive throughout. Further evidencing this approach, we found these conversations recorded in some clinical records to provide the Senior Responsible Clinician with key information, ahead of any DNACPR discussion. This is a positive example of building a good rapport with people, and to support their understanding around DNACPR.

We acknowledge that not all situations can happen in a planned way, as there are often challenges faced by clinicians in conducting a conversation around a DNACPR decision. During our staff focus group at Aneurin Bevan, we heard examples where a patient may attend ED in an emergency, and clinicians have limited time to hold sensitive discussions, which can be challenging. We also heard about clinician efforts to hold sensitive conversations around DNACPR at an earlier stage in the person's illness, and to hold these within the community where possible.

Our review has noted several examples of positive practice relating to DNACPR discussions; however, some aspects can be strengthened to ensure appropriate and informative discussions are held with all patients and their families. Understanding the patient's wishes at the end of their life is a central element of good care. Holding appropriate conversations and making a DNACPR decision before a patient becomes too unwell, or loses the capacity to do this, should be the aim. Clinicians must consider how and when to approach the discussion sensitively, and wherever possible, should understand the patient's clinical condition, their wishes, attitude, and cultural beliefs, to allow sufficient time for a meaningful and informative conversation. They should also be aware that on first discussion, this may not be welcome news for patients and those close to them.

Recommendation 4:

Health boards and trusts should explore how clinicians can consider holding DNACPR discussions as early as appropriate with patients and those close to them, to allow them time to understand the decision, reflect on discussions and to generate follow-up discussions if appropriate.

Recommendation 5:

Health boards and trusts must ensure that following DNACPR discussions, clinicians clearly document the details and decision rationale on the DNACPR form and within clinical records (where necessary).

Recommendation 6:

In line with the all-Wales Policy, health boards and trusts should ensure that clinicians fully engage in appropriate discussions with patients and family, to

ensure an individual's life is respected and valued, and to make clear that a DNACPR decision does not prejudice any other aspect of care.

Consideration of equality and diversity in DNACPR discussions and decisions

Any DNACPR discussion should be approached with recognition of the individual's particular circumstances, their values, and their religious or cultural beliefs. In addition, any DNACPR decision should never discriminate against anyone, including those with protected characteristics.

A clinician's knowledge and understanding should be supported with resources around equality, diversity, and inclusion. When considering this in our staff survey, we received the following comment:

"We have had good feedback [regarding] DNACPR conversations, in particular from patients and from those close to them for whom this has been of utmost importance. Resources and learning shared with groups like Muslim Doctors Cymru have been very helpful in sharing with people of faith who have had queries about CPR/DNACPR, who have mistakenly linked it to euthanasia (which is not permitted in Islam)".

We sought to understand how health boards and trusts ensure clinicians consider equality and diversity when making DNACPR decisions. Overall, the responses from health boards indicated that clinicians take a person-centred approach with individuals. We found an example in one organisation where an equality and diversity lead were in post to support staff with DNACPR discussions.

We were provided with data and information of how health boards and trusts offer training opportunities to staff and provide access to online resources relating to equality and diversity. This included information on gender equality in palliative and end of life care, supporting those with learning disabilities when discussing and making decisions about DNACPR or end of life care, DNACPR discussions with people from Islamic cultures, and information about gender or transgender needs during end-of-life care. We also found that health boards and trusts utilise the [DNACPR Equality Impact Assessment](#).

We asked staff in our survey whether they felt that appropriate training and support was available relating to equality and diversity when making DNACPR decisions. Only 40% felt their organisation provides appropriate training or support. This contrasts with the information provided to us pre-fieldwork from health boards and trusts.

Within the staff survey, some said they did not have sufficient awareness to fully enable them to consider equality and diversity when making DNACPR decisions.

Some also felt they had insufficient time to undertake training to familiarise themselves with the needs of people across diverse cultures. We did, however, receive a positive comment, reflecting access to other resources, which includes access to the report; [I just want to be me, Trans and Gender Diverse Communities' Access to and Experiences of Palliative & End of Life Care](#), and a comment included:

“Our Trust has information, resources and training packages on this, [including] the recent Hospice UK report on LGBTQ+ resources for DNACPR and [Advance and Future Care Planning Group]”.

We received a balanced response from staff relating to the support available when considering a person’s spiritual and cultural beliefs during DNACPR discussions. One respondent said they were yet to be challenged by any issues relating to DNACPR decisions and spiritual/cultural beliefs. However, when considering all beliefs, it was felt there to be a lack of available information to support staff. However, we did receive a positive comment which said:

“Useful to have recently read about Islam and its approach towards [end of life] care and DNACPR, following a presentation on DNACPR in our trust, we had a Muslim family who were concerned that it went against Islam. We were quickly able to allay these concerns due to the teaching provided. DNACPR is part of acceptable practice in Islam”.

When we considered the documentation for capturing a patient’s needs, beliefs and values, 41% in our staff survey felt it was insufficient. We also asked the public whether their needs, beliefs and values were considered, and disappointingly, 58% felt this was not taken into consideration.

Our review has found that overall, the provision of resources and support for staff regarding equality and diversity is satisfactory and consistent across Wales. However, informing staff about the information available, and supporting them with adequate time to access this or undertake training, is an area that requires strengthening. This includes access to training other than mandatory equality and diversity, and to other resources specific to diverse cultures, religions, and gender equality.

Recommendation 7:

Health boards and trusts should consider how staff can be supported with appropriate time to undertake training, and access the information resources available, to support them with considering people’s spiritual needs, values, and beliefs, when making DNACPR decisions.

Recommendation 8:

The all-Wales Advance and Future Care Planning Group should consider whether the current DNACPR and/or Advance and Future Care Plan policy and relevant

documents can cater for individuals' spiritual needs, values, and beliefs, so this information can be more readily accessible and can be considered by all clinicians involved in a person's care.

Communication challenges

We considered how health boards and trusts ensure clinicians adequately engage with people who have communication difficulties, such as those with language barriers and sensory or cognitive impairments. We found several measures in place for people with communication challenges, which included accessing Welsh speaking members of staff to assist patients whose first language is Welsh.

Across Wales, staff have access to the [Welsh Interpretation and Translation Service](#), which is also available in over 120 languages, including British Sign Language. We heard examples that discussions are often held in other languages, supported by bilingual staff. The Language Line translation service is also available to NHS Wales, and can be provided by video, face-to-face or telephone. We also found that where necessary, involvement of a learning disability advocate can support the discussions around the DNACPR decision making process.

We found examples of accessible staff resources to support them with communication challenges. This included hearing loops, translation services, learning disability and gender equality resources, and help for people with literacy challenges. In one health board, we found a good example where a sensory loss tool kit had been developed, which provides guidance on supporting patients with sensory needs.

We also found that staff can access [SignLive](#) for support when having DNACPR discussions with patients who have sensory issues, such as hearing impairments, and other examples which support patients with sight impairments. The Talk CPR resource has audios for those with visual and sight issues and has videos for people with deafness and hearing impairments, which explains the DNACPR decision process. This is positive in enabling patients and their families to understand the DNACPR decision making process.

We also found examples in clinical records, where communication needs and equality and diversity had been identified, which demonstrated that efforts to accommodate their needs had been explored and met.

We asked staff in our survey how well their organisation supports them to have inclusive and accessible DNACPR discussions when faced with communication challenges; 58% felt their organisation was somewhat or very effective, 32% felt not at all effective, and 10% were not sure. A theme notable within the comments was their lack of awareness about the support available to staff. One comment suggested they were not aware of any support available to staff; however, it did

not mean that it was not available, just not very well communicated. Other staff comments included:

“I have not had language barriers, but if I had a non-English speaker, it would be problematic”.

“We don’t do this as well as we could and would be useful to have awareness of tools which may facilitate better conversations and inclusivity”.

We asked a similar question in our public survey around people’s accessibility needs during DNACPR discussions. Disappointingly, almost half felt their accessibility needs were not considered. In addition, most respondents felt their communication needs or preferences were not discussed beforehand. Comments included:

“My Father was blind and [it] was not explained fully what this meant”.

“Patient is very hard of hearing and wears hearing aids and did not have them in place at the time of arrival of [clinician]. He was not asked if he could hear/ understand at any point, and I had to stop the conversation immediately to tell her he needed hearing aids and for her to stand closer so he could hear”.

We also received some positive comments around the support of patient resources which included:

“I can’t focus on leaflets for very long, I prefer an explanation, or a video. I saw a video on it, after the conversation, which was very helpful”.

“English is not my first language, but resources were easy to understand. To be honest, more people should know about successes and failures of CPR even before they get admitted”.

It was positive to find some staff feel supported by their organisation to have inclusive and accessible DNACPR discussions, but unfortunately this is not consistent across Wales.

Information provided to us by health boards and trusts indicate that resources are available to support inclusivity. This was also corroborated by some staff and patient feedback, with these resources accessible via one [central site \(through the NHS Wales DNACPR website\)](#). However, overall, our review has found a lack of staff awareness of the resources available to them around inclusive and accessible DNACPR discussions. Therefore, more must be done by health boards and trusts to raise staff awareness.

Recommendation 9:

Health boards and trusts should consider its staff awareness of the support, resources and training available to them about inclusive and accessible DNACPR discussions, and how to improve the promotion of its availability.

Are DNACPR decisions clearly recorded and communicated between healthcare professionals?

The following sections will focus on the second part of our key question, in particular around how DNACPR decisions are recorded and communicated between healthcare professionals. This will draw on evidence gathered during our analysis of the relevant sections of the DNACPR form, as well as other evidence.

Does the patient have capacity to make and communicate decisions about CPR?

In line with the all-Wales Policy, clinicians must consider whether patients have mental capacity to make and communicate decisions about CPR. If the patient does not have capacity to weigh up and retain details for a DNACPR decision, a Mental Capacity Assessment must be undertaken, and the best interests of the patient must be considered and recorded within their clinical records. If a patient does not have a person close to them who is willing and able to be consulted about DNACPR, then an IMCA should be instructed. Clinicians must also ensure that any existing [Advance Decision to Refuse Treatment](#) (ADRT) or LPA for health and welfare document is specific, valid, and applicable to the patient's current circumstances.

Our review of DNACPR forms found this section was generally well-completed, with most reflecting patients having capacity to make their own decisions. However, some demonstrated conflicting information. One example included a patient who was deemed not to have capacity, but the DNACPR discussion had occurred with the patient alone. We did not have access to clinical records to establish whether additional information was documented within the relevant clinical records.

We also found examples where patients were marked 'NO', not having capacity, however, the sub-questions regarding ADRT and LPA were not completed. We, therefore, could not establish whether the patient had made a previous DNACPR decision to refuse treatment, or had instructed someone to make decisions regarding this on their behalf. We also found examples where neither 'YES' or 'NO' were indicated, thus not allowing us to establish whether the clinician had considered the patient's capacity or whether key documents were in place to support this.

During our fieldwork in Aneurin Bevan, we found examples of ambiguous information documented around patient capacity. This included a DNACPR form indicating the patient did not have capacity, and no documentation relating to an LPA, or rationale that the decision was in the patient's best interests when making a DNACPR decision. Neither was evidence of this documented in the clinical records. Another example included a form stating a patient did not have capacity, however, the clinical records, reflected that the patient, perhaps, did have

capacity, since there were entries made by two staff who documented the patient was able to correctly, albeit with difficulty, answer questions appropriately.

Due to our collective findings regarding capacity assessments in Aneurin Bevan, we were not assured that these were being undertaken appropriately. We therefore addressed this with the health board through our immediate concern process as highlighted earlier.

In Hywel Dda, we found some positive examples of clear documentation around capacity. This included well-documented accounts of patient cognitive function, and good evidence of legal measures taken for a patient who did not have capacity, a next of kin or other family. Reference to the patients' capacity was recorded primarily in the medical records and was also clear within the nursing records. We also found good examples of best interest decisions and Mental Capacity Assessments, in clinical records, which was supported by clear documentation of discussions with relatives, who had LPA.

We considered the findings around capacity in our staff survey and 60% felt that individuals are encouraged to participate in conversations about their DNACPR decision, regardless of capacity. However, there were mixed comments suggesting parts of the DNACPR form were not being completed, particularly for LPA and ADRT.

We also considered comments about capacity within our public survey. It was disappointing to see one respondent said:

"The consultant clearly did not understand people's human rights, the value of life or the impact on family to state without discussion that my father was no longer of any value. I have a good understanding of mental capacity assessment and the legal requirement to support people to fully understand any treatment offered or withdrawn having worked across Gwent social services for 20 years. I understood, the consultant did not".

We asked staff in our survey to share their thoughts on how the DNACPR process could be improved. Comments included the need for improvement on the DNACPR form for recording mental capacity and the form should encourage or reference a more thorough mental capacity assessment. It was positive to find other comments referencing the [National Mental Capacity Forum webinar on DNACPR](#), which accounts the different approaches to DNACPR, and elaborated this as an excellent resource that all clinicians responsible for DNACPR should watch. This is available through the [NHS Wales DNACPR website](#).

Comments in our staff survey and focus groups also highlighted that additional training would be beneficial for completing mental capacity assessments, and how to record the evidence for concluding the capacity decision.

Whilst there was some evidence of positive practice relating to patient capacity, undertaking assessments and consideration, or establishing an ADRT or LPA should be improved. Strengthening the process for mental capacity assessments is also an area HIW has found in other aspects of its assurance work. Therefore, completing these assessments should be strengthened more widely across health boards and trusts, and is not exclusive to the DNACPR decision process.

Recommendation 10:

In the absence of patient capacity to engage in and understand a DNACPR decision, health boards and trusts must ensure that clinicians complete all relevant parts of section 1 of the DNACPR form. Additionally, a mental capacity assessment and the decisions around the best interests of a patient should be appropriately recorded and filed in the clinical records.

Recommendation 11:

Health boards and trusts should undertake a training needs analysis relating to the Mental Capacity Act and completion of mental capacity assessments. This should be considered widely across the organisation and not exclusively for those completing a DNACPR decision form.

Summary of the main clinical conditions and reasons why CPR would be inappropriate, unsuccessful, or not in the patient's best interests

Section 2 of the form mandates that a clinical summary is completed and should include the reasons why CPR would be inappropriate, unsuccessful, or not in the patient's best interests. The all-Wales Policy states this should be succinct but as specific as possible, and that more detailed information can be recorded in the patient's clinical record.

On most DNACPR forms, we found this section was well-completed. Our ability to evaluate this during our remote review of DNACPR forms was more challenging, due to our inability to consider corresponding clinical records. As noted earlier in the report, we acknowledge that the free text box in section 2 has minimal space for recording the required information. Nevertheless, we saw positive examples of concise and thorough summaries of patients' main clinical conditions, with clear indications why CPR would be inappropriate. However, we found some examples using jargon and/or abbreviations on forms, which were not clear to justify why CPR would be inappropriate.

We found other examples where section 2 had not been completed at all. As previously discussed, a balance must be struck between a brief record that is concise and quickly reviewed in an emergency, when every second counts, versus having more detailed information to read. The DNACPR form can co-exist with

other forms, such as the [all-Wales Advance and Future Care Plans](#) form which can be accessed online for more detail and more nuance on a person's wishes.

Within Aneurin Bevan, we found that documentation was generally of a lower standard, which included recording the patients' clinical condition and why CPR would be inappropriate. Some examples had limited, or insufficient information recorded, and some where the handwriting was illegible. Other examples evidenced completion of section 2; however, there was no rationale why CPR was considered inappropriate. We addressed our concerns for this with the health board as part of our immediate concerns process as highlighted earlier.

Whilst we found some good examples of clear and comprehensive documentation for section 2, our conclusion is that improvements can be made. It is important that section 2 is completed well. The form should capture a succinct clinical summary, and reasons why CPR would be inappropriate. This can be supported with additional information within the clinical records, as highlighted in the all-Wales policy.

Recommendation 12:

Health boards and trusts must ensure that clinicians clearly and succinctly record a patient's clinical summary within section 2, and the reasons why CPR would be inappropriate, in line with the all-Wales Policy.

We have reported on sections 5 and 6 of the DNACPR form together, as they relate to clinicians completing and/or having oversight of the form:

Healthcare professional completing this DNACPR form, and Senior Responsible Clinician (SRC) with oversight

The all-Wales Policy states that the clinician completing section 5 of the form should have knowledge of the patient's current and past medical history. Those completing the form must clearly sign and date it and provide their professional registration number. The DNACPR form must be overseen by an SRC (usually the Consultant or General Practitioner (GP), and in some settings, a Consultant Nurse, or Advanced Nurse Practitioner). The SRC should be consulted as soon as reasonably possible about the DNACPR decision, this can be done remotely, but must be recorded. This must be signed and dated, together with the SRC's professional registration number.

We found that section 5 was generally well-completed, however, contact details, such as bleep or telephone numbers were frequently omitted. The completion rates in section 6 regarding the SRC, was variable. Some were completed, others were not. The all-Wales Policy highlights that section 6 should be signed by the SRC at the earliest possible opportunity. However, the signature at section 5

already denotes the DNACPR decision, and should be regarded as such, in the event of a cardiopulmonary arrest or natural dying. All details in section 5 and 6 must be completed, to ensure others can contact individuals about the decision made on the form.

Delays in completion of section 6 was a finding in most organisations and not isolated to one. We also found examples of delays of several days, and in some, there was more than a month delay in completing section 6. These delays were also highlighted in our staff survey. This highlights the importance of holding DNACPR discussions as early as possible, however, we acknowledge that a patient's clinical condition may deteriorate rapidly, therefore, it will not always be possible to maintain a timely completion of section 6 by an SRC.

Recommendation 13:

Health boards and trusts must ensure that section 6 of the DNACPR form is completed in a timely manner by the Senior Responsible Clinicians in line with the all-Wales Policy.

Cancellation of the DNACPR decision

There may be situations where it is appropriate for a clinician to cancel a DNACPR decision. The all-Wales Policy states that when this is necessary, the original form should be clearly crossed through with two diagonal lines in black ink, with “*CANCELLED*” written between them and must be signed by the relevant clinician.

The SRC involved in the patient's care must also be consulted about this decision if they have not initiated this themselves. All previous recipients of the DNACPR decision form must be notified immediately. The communication must be in writing and logged in all relevant records, and where possible, contain a copy of the original overwritten cancelled document. The patient's own form should be returned and filed in the clinical record, to reduce the risk of rescuers not attempting CPR. If a patient has destroyed their copy, this must also be recorded in the clinical record.

We considered (where appropriate), whether the cancellation of a DNACPR decision had been correctly completed. We found two examples where a cancellation of the DNACPR decision had been made, and both were appropriately completed. However, we were unable to establish whether cancellation of the DNACPR decision had been communicated to all form copy holders in line with the all-Wales Policy.

Disseminating copies of the DNACPR decision form

The all-Wales Policy stipulates that clinicians must ensure communication of a DNACPR decision is made across relevant teams, such as to the GP, Care Home, or out-of-hours care providers. The patient or those close to them should also receive

a copy the form. The Policy also reflects that health boards and trusts should ensure out-of-hours services, EDs and GP surgeries have systems that can store, coordinate, manage and respond to DNACPR data. This should include a protocol for alerting WAST when patient transport is requested for a patient with a current DNACPR decision in place.

Any Welsh language DNACPR forms must be appended with an English language version. We received a comment in our staff survey where a Welsh language DNACPR form had been completed, however, there was no English language version appended. As a non-Welsh speaker, they said they were unable to read or translate the content of the form. This example highlights the importance of ensuring an English language version of a DNACPR form must always be appended to a Welsh language form, to safeguard that all relevant people can understand that documented on the form.

Our review found several forms that did not contain a section 8, as they were older and previous versions of the DNACPR form. However, where this section was present, it was by far, the least completed. This could mean that a copy of the form is not provided to relevant others when the patient was discharged, however, we could not establish this in the records.

We discussed the completion of section 8 with staff during our focus groups. Examples were shared with us of the challenges faced by paramedics or ambulance crew in attending the home, or care home of a patient, and a DNACPR form had not accompanied the patient home. Therefore, no evidence that a DNACPR decision had been made. This was supported by a comment in our staff survey which said:

“While the DNACPR form is usually filled out correctly the communication with other areas of healthcare is not always very good. There may or may not be a brief mention on the discharge paperwork of their being a DNACPR form in place, but rarely any detail about discussions. I have also come across nurses not realising that they need to give the patient a copy of the DNACPR form when they are discharged. Also, we are unable to see on the parts of the GP record we have access to whether a patient has a DNACPR form in the community. All of this means that we are often not aware of whether a patient has a DNACPR form and the reasons for this”.

The comment above, highlights the risk that in the event of a patient cardiac arrest or natural death at home, clinical staff are likely to commence CPR on a patient, against their wishes, if there is no evidence that a DNACPR decision has been made.

Communication across healthcare teams

We considered how well clinical teams communicate DNACPR decisions. In our staff survey, we asked people to tell us how they rated the communication of DNACPR decisions across healthcare teams. It was concerning to find that almost 30% felt that communication of DNACPR was not at all effective, and a further 58% felt they found it just somewhat effective. We received several staff comments around communication, which included:

“Needs to be more obvious on CWS [electronic clinical record system] when a DNACPR has been made and if it is an ongoing one or not, so it is easy to find in future admissions (and not buried in large amount of random documentation)”.

“Limited communication, not available to community teams, even when recorded digitally can be difficult to find”.

“It varies, very effective in our team but not as effective in some teams and settings. For example, some medics will write in the notes that a patient is not for escalation or not for CPR but not complete the form and it may not be clear if they have had a conversation with the pt and what was said in that conversation.”

A theme which emerged from the comments was the need for effective information sharing, particularly with references to the implementation of an electronic DNACPR form. Some staff comments included:

“Problem of accessing discussion held on previous admissions and sometimes finding DNACPR records from previous admissions. one issue is that discussions not always attached to the DNACPR form (due to lack of space) and finding where they are written in old notes can be a challenge”.

“Electronic DNACPR forms may help with sharing information between primary, secondary and tertiary teams”.

“A central database of DNACPR decisions that removes the keeping of these important documents from the unwell patient / carer. This system could then be accessed by those supporting the patient/family/carers”.

Our survey results clearly reflect an issue with the communication of DNACPR decisions across healthcare teams. Poor communication increases the risk that a patient may receive CPR against their decision and wishes. Therefore, more needs to be done across Wales to ensure communication of DNACPR decisions is improved across clinical teams.

Electronic repository for DNACPR decision forms

Our overall findings recognise the benefits that an electronic system could bring in supporting the communication of DNACPR decisions, and enable sharing electronically with patients, for instance, via resources created for NHS Wales

patients to access their own health records. This would be beneficial in bridging the gap between community and primary care settings and acute hospital settings, and from one health board area to another.

The benefits of a repository would also enable patients, clinicians, GP practices, Out-of-Hours services, WAST staff and the NHS 111 service to access a central system. This would establish if a patient had a DNACPR decision form in place or has an advocate to make care decisions, Advanced Decision to Refuse Treatment or an Advance Care Plan in place.

We learnt during our review that efforts had been made by the all-Wales Advance and Future Care Planning Strategy Group to introduce a central electronic repository for DNACPR decision forms. This would accompany or replace the hard copy of the form and would help ensure the form is easily found promptly. However, funding is yet to be secured to implement this.

The introduction of an electronic system would not be without risk. However, there have been examples in the UK media regarding serious communication failures around the provision of CPR to patients, even where electronic record sharing of CPR status has been in place. This includes an example in England highlighted in a [Senior Coroner Regulation 28: Report to Prevent Future Deaths](#), where a patient with a DNACPR decision in place choked on a piece of food. Whilst the patient had a DNACPR decision form in place which he had agreed, it was for an altogether different health reason. Due to this, the patient did not receive prompt assessment by emergency staff, nor made a priority for a paramedic response. The choking was a potentially reversible cause that may have sustained the life of the patient for longer, irrespective of their long-term conditions. However, miscommunication prevented any life support.

Other examples of poor communication are highlighted in the report; [What People Need from a DNACPR Decision and Discussion: Findings from Focus Groups with Older People](#), about people having a DNACPR decision in place, however, despite this, patients were resuscitated against their wishes.

Overall, the existence of an electronic DNACPR repository may mitigate against such issues, since the forms would be completed online and would be accessible to all healthcare providers across Wales, including patients and their families. The benefits of the electronic system may include:

- Improved documentation of key clinical details regarding about the DNACPR decision in one accessible system
- Immediate notification to ED staff when patient may arrive in an emergency, such as cardiac arrest
- Immediate notification to the repository if a DNACPR decision is cancelled.

In addition, the system may mitigate against the risk of:

- The need to document additional information in clinical records (which are then not accessible outside hospital)
- The physical loss of paper DNACPR forms
- Other healthcare providers not being alerted to a DNACPR decision (such as WAST or GP).

This list is not exhaustive but provides examples of the benefits of an electronic repository. In addition, an electronic system could ensure that each section of the form is completed in full (as mandatory fields), which would mitigate against our review's findings of not completing sections.

Recommendation 14:

Health boards and trusts must ensure that communication of a DNACPR decision is improved across to the relevant clinical teams involved in the care of patients, and these within section 8 of the DNACPR form, such as their GP, care home and out of hours providers where appropriate.

Recommendation 15:

Welsh Government should consider the benefits of an all-Wales electronic patient repository for recording DNACPR decisions, for instance within Welsh Clinical Portal, to help achieve prompt and robust communication of these decisions throughout Wales. This would benefit patients and those close to them, communication nationally across different health board teams in secondary care, and community and primary care, and in care homes, and emergency services.

Training for DNACPR decision making

Undertaking DNACPR training is not mandatory in Wales but is considered best practice. The all-Wales Policy highlights that employers should support clinicians to access training for Advance and Future Care Planning and DNACPR processes and have easy access to relevant policies.

Health board and trust induction programmes for clinical staff should raise awareness of the all-Wales DNACPR policy. Primary care professionals must also be provided with access to any Advance and Future Care Planning or DNACPR training provided by their local Health Board or trust. The policy also highlights the importance that it spans the 'whole system of care', and all relevant NHS staff should have easy access to knowledge sources, senior clinical support and to training opportunities to deliver an effective process for DNACPR conversations.

Clinicians who complete DNACPR decision forms should undertake regular training on DNACPR, as part of their professional appraisal and revalidation cycles. As discussed earlier, training is accessible across Wales via the Electronic Staff Record and the e-learning programme; End of Life Care for All (e-ECLA). The [Wales](#)

[DNACPR website](#) also provides ample resources, including ESR modules that staff holding such conversations can access.

In our staff survey, we asked what training staff had received in the last 12 months to assist with their understanding, recording and communication of DNACPR decisions and equality and diversity. Across Wales, Mental Capacity Act, and Equality, Diversity and Human Rights training is mandatory, but the results of our survey demonstrated that more must be done to ensure and support staff to complete DNACPR training.

The e-ELCA programme (as highlighted above), provides resources to enhance the knowledge and skills of health and social care staff, to ensure well-informed and high-quality care can be provided by confident and competent staff and volunteers. Less than 23% of staff had completed the e-ECLA and DNACPR Communication skills learning modules.

Most respondents to our staff survey said they had read the current all-Wales DNACPR policy, and had undertaken the ‘Equality, Diversity & Human Rights’ and ‘Mental Capacity Act’ e-learning. Some staff also said they had undertaken other related training which included Palliative Care and Cancer training courses, MSc Advanced Clinical Practice, MSc modules on ethics, and communication in end-of-life care.

We asked staff to tell us whether any different or additional training would be useful. The responses included:

“A conference on DNACPR and AFCP, perhaps organised by HIW (together with CIW) and/or HEIW may be useful. There was a great national Welsh conference on future care planning in 2019, we should aim to repeat these events every few years”.

Other staff comments included:

“Listened to multiple podcasts which detail the all-Wales DNACPR Policy, End of Life care and I have visited the Talk CPR website”.

“The NHS Wales module on the Care Decisions for last days of life guidance which is found on ESR and covers the dying process and decision making at [end of life]”.

Regarding what improvements could be made to the DNACPR process, staff suggested improved access to training across various clinical teams, and the need to educate clinicians in the most suitable way of carrying out empathetic DNACPR discussions.

DNACPR Audit and data collection

Welsh Government and NHS Wales organisations are committed to the principles of value-based healthcare to help meet the challenges of rising costs and increasing

demand, while continuing to improve the quality of care. Clinical audit is an integral component of the quality improvement process and is highlighted in the all-Wales policy. It states that health boards and trusts should undertake an audit of at least 50 DNACPR forms every two years, to establish whether the DNACPR decision making process and communication is robust, and to identify areas for improvement.

We considered the last three DNACPR audits which had been undertaken in each health board and Velindre. The dates of audit data varied across organisations and ranged from 2018 through to 2023. Overall, the compliance rates we saw were high. We were also told that health boards and trusts consider the audit outcomes and the results with any action required are escalated through their individual governance processes. However, we did not triangulate this data across all health boards.

We considered the audit data submitted to us by Aneurin Bevan from February 2023, which demonstrated a compliance of 95%. However, during our review of DNACPR forms remotely and onsite alongside clinical records, there was a discrepancy in our findings, as highlighted earlier. We were subsequently not assured that the DNACPR audit processes in place was representative. We addressed this with the health board through our immediate assurance process as highlighted earlier.

We asked staff in our survey to tell us whether their organisation undertakes regular audits of the DNACPR process and documentation, almost half said they were not sure. This therefore highlights that any identified issues or learning from audit is not effectively shared across teams. One comment we received implied that their organisation should audit the DNACPR process and completion of the forms.

Health boards and trusts should reflect on the lack of staff awareness around the audit of DNACPR decision making process and consider whether their overall processes need strengthening. This should include sharing the learning following audit across all relevant teams. We were made aware of a good example of an audit quality improvement project, undertaken in one Welsh Trust; [Do not attempt cardiopulmonary resuscitation documentation: a quality improvement project](#). The learning from this was communicated to staff through a presentation and at several teaching events and has also been shared nationally.

Recommendation 16:

Health boards and trusts must consider their audit processes for the DNACPR form in line with the all-Wales Policy, to ensure when this is conducted, the process is robust, and that learning is shared across their organisation.

Capturing and acting on staff and patient feedback

It is clear throughout our review that lessons can be learned from both the staff and the public's feedback about their experiences of DNACPR decisions. Our findings and recommendations identified throughout this review also resonate with that highlighted in the report; [What People Need from a DNACPR Decision and Discussion](#), which was published in March 2024 by the charity [Compassion in Dying](#). Therefore, health boards and trusts should consider these comments and determine how these could influence improvement with the quality of the DNACPR decision making process, and the experience of patients and those close to them across Wales.

Recommendation 17:

Health boards and trusts must consider the staff and public's experience and comments highlighted throughout this report and determine how these could influence improvement with the quality of the DNACPR decision making process, and the overall patient experience.

Conclusion

It is clear from our findings that there are examples of noteworthy practice across Wales regarding the DNACPR decision making process. However, we have also identified opportunities to improve. These include the need to strengthen the quality of communication with both patients and those close to them, and across different healthcare teams. This is to ensure that discussions and DNACPR decisions and the rationale behind these, are clearly recorded and communicated between healthcare teams.

Staff need to feel supported and empowered to hold open and honest conversations with people, and equally patients and their families should be supported and encouraged to talk about what they would like to happen at the end of their lives. Early DNACPR conversations can support the overall DNACPR decision making process and can help ensure people understand what will or will not happen once the decision not to resuscitate is made, to maintain a respectful and dignified time during death.

Health boards and trusts should ensure that the resources they provide to support staff to hold DNACPR discussions are shared, accessed, and utilised. Our review has found training is a theme that needs attention.

Further attention to detail is required by staff when recording information on the all-Wales DNACPR form. The form should be completed in full, and staff should ensure any additional or supporting information is legibly recorded within clinical records about the decision-making rationale, including conversations with patients and their families.

The communication of a DNACPR decision should be clear and without ambiguity, to ensure relevant people involved in the care of the patient, are aware of the decision and plans. This includes departments across health boards or trusts, GPs, care homes and out-of-hours providers, as appropriate.

DNACPR decisions are an important part of end-of-life care that can ensure a respectful and dignified death. Yet, it is important that these decisions are communicated sensitively and effectively. Through our review we hope to drive improvement in relation to these decisions and ensure that clinical intervention aligns with and respects the wishes of patients.

What Next?

We expect health boards, trusts, and Welsh Government to carefully consider the content of this report and the overall findings from our review. Organisations must also consider and act upon the recommendations set out within the report.

We also expect health boards and trusts to consider the staff and public's feedback highlighted throughout the report and determine how these can influence improvement with the quality of the DNACPR decision making process.

We hope this review will be used to help health boards and trusts improve their processes relating to the DNACPR decision making process, and the communication between clinicians and patients and those close to them. Healthcare teams across Wales should be encouraged to collaborate and benchmark with each other to share and learn from good and innovative practice.

All relevant stakeholders highlighted within this report are required to submit an improvement plan in response to the review's recommendations. This is to ensure that the matters raised by our review are being addressed. HIW will continue to review progress against recommendations through its review follow-up process. The findings highlighted in our report, and the responses that we receive, will support HIW in considering other work in the future.

Appendix A

Recommendations

As a result of the findings from this review, we have made the following recommendations.

	Recommendations:
1	Health boards and trusts should ensure that clinicians completing the date section 'for review' within a DNACPR form, must clearly document all the required information including the date and their professional registration numbers, to ensure that clinicians are identifiable if required.
2	Health boards and trusts should ensure that clinicians are providing or signposting patients and those close to them with sufficient information resources, in an appropriate format, to help them understand and consider the CPR process, and what DNACPR means.
3	The Advance and Future Care Planning Group (Wales) should consider how to further increase public awareness within health boards and trusts regarding the existing resources and the meaning and process for DNACPR decision making, to ensure people can appropriately engage in conversations about their preferences during the end of their lives.
4	Health boards and trusts should explore how clinicians can consider holding DNACPR discussions as early as appropriate with patients and those close to them, to allow them time to understand the decision, reflect on discussions and to generate follow-up discussions if appropriate.
5	Health boards and trusts must ensure that following DNACPR discussions, clinicians clearly document the details and decision rationale on the DNACPR form and within clinical records (where necessary).
6	In line with the all-Wales Policy, health boards and trusts should ensure that clinicians fully engage in appropriate discussions with patients and family, to ensure an individual's life is respected and valued, and to make clear that a DNACPR decision does not prejudice any other aspect of care.
7	Health boards and trusts should consider how staff can be supported with appropriate time to undertake training, and access the information resources available, to support them with considering people's spiritual needs, values, and beliefs, when making DNACPR decisions.
8	The all-Wales Advance and Future Care Planning Group should consider whether the current DNACPR and/or Advance and Future Care Plan policy and relevant documents can cater for individuals' spiritual needs, values, and beliefs, so this information can be more readily accessible and can be considered by all clinicians involved in a person's care.

9	Health boards and trusts should consider its staff awareness of the support, resources and training available to them about inclusive and accessible DNACPR discussions, and how to improve the promotion of its availability.
10	In the absence of patient capacity to engage in and understand a DNACPR decision, health boards and trusts must ensure that clinicians complete all relevant parts of section 1 of the DNACPR form. Additionally, a mental capacity assessment and the decisions around the best interests of a patient should be appropriately recorded and filed in the clinical records.
11	Health boards and trusts should undertake a training needs analysis relating to the Mental Capacity Act and completion of mental capacity assessments. This should be considered widely across the organisation and not exclusively for those completing a DNACPR decision form.
12	Health boards and trusts must ensure that clinicians clearly and succinctly record a patient's clinical summary within section 2, and the reasons why CPR would be inappropriate, in line with the all-Wales Policy.
13	Health boards and trusts must ensure that section 6 of the DNACPR form is completed in a timely manner by the Senior Responsible Clinicians in line with the all-Wales Policy.
14	Health boards and trusts must ensure that communication of a DNACPR decision is improved across to the relevant clinical teams involved in the care of patients, and these within section 8 of the DNACPR form, such as their GP, care home and out of hours providers where appropriate.
15	Welsh Government should consider the benefits of an all-Wales electronic patient repository for recording DNACPR decisions, for instance within Welsh Clinical Portal, to help achieve prompt and robust communication of these decisions throughout Wales. This would benefit patients and those close to them, communication nationally across different health board teams in secondary care, and community and primary care, and in care homes, and emergency services.
16	Health boards and trusts must consider their audit processes for the DNACPR form in line with the all-Wales Policy, to ensure when this is conducted, the process is robust, and that learning is shared across their organisation.
17	Health boards and trusts must consider the staff and public's experience and comments highlighted throughout this report and determine how these could influence improvement with the quality of the DNACPR decision making process, and the overall patient experience.

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