Arolygiaeth Gofal Iechyd Cymru
Healthcare Inspectorate Wales

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

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

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 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