A Clinical Policy for Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) for Adults in Wales

Equality Impact Assessment

1. Introduction

The Equality Act 2010 places a positive duty on public authorities to promote equality for nine protected characteristics* and requires Welsh public bodies to demonstrate how they pay 'due regard' to equality when carrying out their functions and activities. In the context of this work, health boards and NHS Trusts are required to assess the impact of policies and services on equality and human rights. The purpose of this is to ensure that as far as practicably possible, the opportunities for promoting equality and human rights for people with protected characteristics are maximised and any actual or potential negative impact is eliminated or minimised.

2. Policy Aims and Context

Cardiopulmonary resuscitation (CPR) of patients can be an important, life-sustaining intervention. 'It was originally developed to save the lives of younger people dying unexpectedly, mostly from primary cardiac disease. However, CPR has come to be seen as a procedure that should be used for patients as a therapy to restore cardiopulmonary function and prolong life, irrespective of the underlying cause of cardiac arrest'. (1)

The purpose of this policy is to provide a policy framework for professionals and NHS bodies in Wales in order to enable a consistent approach to decisions relating to the provision of CPR. Whilst for every individual, death is inevitable, achieving a dignified, sensitive and shared approach to reaching a decision relating to CPR is vital for patients and those who are close to them.

^{*} Race; Sex; Gender Re-assignment; Disability; Religion, belief/non belief; Sexual orientation; Age; Pregnancy and maternity and Marriage and civil partnerships

The decision not to attempt CPR on a patient is a major clinical decision. The aim of this policy is to help achieve a position where a discussion about CPR is accorded the highest level of significance. This should help develop across NHS Wales the correct approach of consistent planning of care with regard to CPR as a treatment option and an approach that is centred on an individual plan for each patient where any decision not to attempt CPR is based on an informed and proper discussion with the patient and those who are close to them.

A core group was established in January 2012 to develop a unified policy framework that would promote high standards of decision making in all care settings and a person centred approach that ensures the highest standards of clinical care and treatment.

The approach to developing the DNA (Do Not Attempt) CPR Policy has been grounded in the public sector equality duty principles of evidence; transparency; engagement and leadership to ensure that it impacts in a fair and positive way. Members of the core group are drawn from clinicians involved in palliative, intensive and emergency care, resuscitation officers, quality and patient safety mangers, representatives from primary care and the independent care sector, community health councils, the General Practitioner Committee, Wales, ethics and equality and human rights. The design of the framework has taken account of best practice from other parts of the UK including the learning from South Central England and Scotland. A leading expert from Guy's Hospital in London has supported the work in an advisory capacity.

Early engagement with a wide range of clinical stakeholders was undertaken with three regional clinical workshops held between October and December 2012. These workshops considered key principles and case studies to test different patient scenarios in a range of clinical and non clinical settings.

Non clinical stakeholders have been key partners in this work and two engagement events were held on 13th September 2012 and 29th January 2013. Separate and focused engagement has also taken place with Mencap Cymru and the Older People's Commission to gain a better understanding of the issues for people with learning disabilities and older people.

Key principles and issues raised by DNACPR have been explored from a broad range of clinical perspectives and also, from the individual patient and family/carer's perspectives. Participation from a range of third sector organisations has raised awareness and understanding of the different and diverse needs of people living in Wales. The draft Policy is the product of this wide engagement.

3. Available Research Evidence: Literature Review

A literature review was carried out as the first stage of the process of gathering evidence to inform this equality impact assessment. The results of the literature review are provided below against each of the protected characteristics. There is some research evidence that has specifically highlighted the particular issue of DNACPR in relation to people with protected characteristics. Broader and more extensive research concerned with understanding the needs and experiences of patients when they require end of life care has also been considered, where relevant to DNACPR.

Age

Demographic evidence demonstrates that people are living longer. By 2005-09 life expectancy in Wales had increased to 77.0 years for males and 81.4 for females. Population projections published by Public Health Wales suggest that the number of persons aged 15-24 will decrease by 4% in 2031 whereas an increase of 79% is forecast for the 75+ age group.

Population age structures in rural areas are older and often this is compounded by outward migration of younger people and inward migration of older people. Current projections indicate that the increase in the proportion of older people will be greater in rural areas. As well as having an older age structure, the population in rural areas is by definition more dispersed leading to difficulties in respect of access to, or the provision of, services. (2) The Public Health Wales Observatory has reported that although life expectancy overall has increased, inequalities in both life expectancy and quality of life in Wales have persisted if not slightly increased. Life expectancy has increased more slowly in the most deprived areas compared to the least deprived in Wales. The gap between the most and least deprived areas is 18.9 years for males and 17.8 years for females. This contrasts with the national inequality gap in life expectancy overall of 9.2 years for males and 7.1 years for females. (3)

Older persons are disproportionately affected by chronic conditions. The Welsh Health Survey reported that 82% of respondents aged 65 years and over suffered from a chronic condition, of whom 54% suffered from two or more. If current trends continue the number of people living with chronic conditions will continue to increase in the future, with people living longer and developing more than one chronic condition. (2)

Research undertaken by the National Confidential Enquiry into Patient Outcome and Death (2102) (1) assessed the case notes of 586 adult patients who had a cardiac arrest, triggering either a call to the resuscitation team that led to the delivery of chest compressions or defibrillation during a 14 day study period in 2010. The median age for the sample included was 77 years.

With an increasingly ageing population it will be important to ensure that DNACPR decisions are not adversely affected by negative attitudes towards older people and negative assumptions about their quality of life.

Research published by the Older People's Commissioner for Wales in 2011 (4) highlighted the findings of Dignity and Essential Care Inspections carried out by Healthcare Inspectorate Wales. Do Not Attempt Resuscitation (DNAR) forms not always being fully completed and up to date was reported as a constant theme and challenge. The Research refers to 'clear, effective communication (as) essential to help older people exercise choice and control in a healthcare setting. A lack of information and advice about health conditions, medical treatment, or the quality of care an older person should expect can cause fear and uncertainty and make a stay in hospital more difficult'(4).

The 'Together for Health – Delivering End of Life Care' Delivery Plan sets out the Welsh Government's expectations of NHS Wales, 'working with its partners, in particular the hospice and social care sector, to reduce inequalities in end of life care up to 2016. It sets out how patients and their families will be supported at the end of life, providing high quality care in all settings for people of all ages'. (5)

Disability

People with Learning Disabilities

Research by the former Disability Rights Commission (DRC) in 2006 (6) found that people with learning disabilities are more likely to die young and to live with physical ill health than other citizens. The research found that people with learning disabilities are more likely to be obese, and to experience chronic and long term health conditions, such as respiratory disease and Diabetes. They are also more likely to be diagnosed with these conditions at a younger age than the general population.

The research identified a range of causes to explain the physical health inequalities including poverty, difficulties recognising symptoms, lack of access to healthy lifestyles, inequalities in access to screening and treatment and the side effects of medication. One of the most significant barriers to healthcare was identified as the perceived negative or discriminatory attitudes of healthcare staff.

Many respondents in the research felt that their physical health or other health needs were neglected, or more readily dismissed, due to their learning disability. This was referred to in the research as 'diagnostic overshadowing', attributing any physical symptom to an underlying mental health problem or learning disability. Research published by Mencap in 2012 (7) highlights how discriminatory and negative attitudes towards people with learning disabilities and their quality of life have adversely influenced DNACPR decisions; 'the doctor took one look at my son and said that he was not for resuscitation'. In another example, healthcare professionals are criticized for making 'discriminatory and incorrect assumptions' about people with learning disabilities following a 'do not resuscitate order. In this instance the reasons given on the CPR form were listed as 'Down's syndrome, unable to swallow ... bed bound, learning difficulties'.

Mencap's research (7) highlights that 'the inappropriate use of DNR orders has remained a constant feature of many Mencap cases. There have been circumstances where DNR notices have been applied without the knowledge or agreement of families and applied hastily in inappropriate situations, solely on the basis of the person's learning disability'.

Mencap's research (7) also suggests that healthcare professionals are often unaware of issues around capacity and consent to the extent that patients are often denied treatment or treatment is delayed. This is referred to as 'flawed best interest decisionmaking' when, despite the process being technically followed, the medical advice given in the best interest decision meeting has been weighted in favour of a decision not to proceed with active treatment and the application of DNR orders. This has led to families sometimes agreeing with the decision, only later to find that there was a better prospect of recovery with treatment than they had been told.

Mencap refer to many accounts from families of treatment not being given under the guise of concern about consent. This raises the important need to properly apply the law on consent which is clear that if a person lacks capacity to consent to treatment, a decision must be made on their behalf in their best interests, and the family should be involved in this decision.

People with Sensory Loss

There is a plethora of research published by sensory loss organisations to evidence the barriers to communication experienced by people with sensory loss when they need to access healthcare. These experiences extend to family and carers with different communication needs who should be involved in the DNR decision making process.

Recent research into the experiences of Deaf people (8) when they need primary and secondary healthcare highlighted that 27 out of 36 people who had recently experienced staying in hospital, were not provided with the services of a British Sign Language interpreter when being asked to sign a consent form. Respondents in this research stated that they often missed information and did not fully understand what the doctor was saying.

There could be a potential negative impact for people with sensory loss if their different communication needs are not recognised and met.

People with chronic and long term health conditions

The Welsh Government has quantified the extent of chronic conditions on the population in Wales. (2) One third of adults in Wales (an estimated 800,000) reported having at least one chronic condition; of people aged over 65 in Wales, two thirds reported having at least one chronic condition, and one third had multiple chronic conditions; and over three-quarters of people aged over 85 in Wales reported having a limiting long-term illness. If current trends continue, the number of people living with chronic conditions will increase with people living longer and developing more than one chronic condition.

A study looking at the palliative care needs of people with chronic obstructive pulmonary disease (COPD) (9), concluded that few people with end-stage COPD are given an opportunity to make decisions about their end of life care and despite the majority saying that they would wish to die at home, the majority are still dying in hospital.

People with Mental Health Conditions

Research in 2006 (6) found that people with mental health conditions experience poorer physical health than the general population. It highlighted that people with mental health conditions are more likely to experience chronic and long term conditions, for example, respiratory illnesses, Diabetes, heart disease and cancer.

Informed consent is an important issue for patients with mental health conditions. The statutory framework on capacity and consent issues is set out within the Mental Health Capacity Act (2005). This must be fully taken into account in any DNACPR decision making process.

Race

Census data shows that in 2011 more than nine out of ten (93.2%) residents in Wales were White British while 6.8% of the population (208,006) were from Black Minority Ethnic (BME) groups. A comparison of census data from 2001 and 2011 demonstrates that the population in Wales has increased across all BME groups with the exception of White Irish.

In the context of age, most of the population aged 65+ is White British. Data also shows that most ethnic groups have been ageing since mid 2001 (exceptions are Mixed White and Black Caribbean and Other Black). Amongst the BME groups, Indian (over one thousand people), Pakistani (almost one thousand people) and Black Caribbean (around 700 people) populations have the highest number of people aged 65+. Recent UK wide population projections identify that ageing trends are expected to continue. By 2026 it is estimated that there will be over 1.3 million people in the UK from BME groups aged 65+, many of whom may experience life limiting illnesses.

In the context of languages spoken, in 2011 97.1% of the population in Wales spoke English or Welsh as their first language. The second most spoken language was Polish (0.6% or 17,001). This was followed by Arabic (6,800), Bengali (5,207) and Tagalog/Filipino (2,749).

The majority of people who do not speak English as a first language could either speak it well or very well, whereas 19,305 people whose main language was not English, could not speak English well or at all.

A number of studies in England have looked at the needs of both Black and Minority Ethnic patients and carers in end of life care and have found that there are factors associated with culture and language which need to be considered to fully meet their needs (10).

Religion and belief

More than half of the population in Wales (57.6%) described themselves as Christian in 2011 whilst almost a third reported having no religion. The second most reported religion was Muslim, which represented 1.5% (45,950) of the population.

There is evidence from research undertaken in England (11) that ethnic and cultural differences can influence patterns of advanced diseases, illness experiences, healthcare seeking behaviour and the use of healthcare services. The values and beliefs that underpin religious traditions and family roles might also be seen as incompatible with palliative/hospice care. Some groups might avoid disclosing prognosis and diagnosis in order to protect the patient or avoid distress. (11).

Most of the evidence on disparities and unmet needs for BME populations when in receipt of palliative and end of life care refers to poor communication between healthcare professionals and the patient/family. 'Moreover, these interactions rely heavily on high quality communication between health and social care professionals and patients and their families. The inability to engage in communication not only affects access to palliative care services but has been shown to be a source of serious problems in clinical consultations and the cause of misunderstandings amongst patients, family members and healthcare providers'.(11) Poor communication has been identified as a serious problem when providing care to BME groups. 'This is associated with a lack of sensitivity to cultural and religious issues (and consequent poor understanding of needs) and lack of translation resources. It is also highlighted that poor communication can 'impede a doctor's ability to assess the patient's mental competence to make informed decisions' (11).

The evidence has also highlighted differences regarding end of life decisions (such as a lower use of advance care planning documents and more choices of aggressive treatment (13). Substantial evidence reports that minority ethnic groups are less likely to complete advance directives than the majority White. 'They are more likely to desire life-sustaining treatment and aggressive treatments such as artificial nutrition and cardiopulmonary resuscitation even where there is no hope for recovery'.

Reasons for these differences are complex and sometimes contradictory. The most commonly discussed issues were mistrust regarding the healthcare system, the importance of religion and difficulties in trying to apply the Western model of autonomy to different cultures. It seems to affect both decisions to undertake aggressive treatments and decisions not to use advance care planning. (11)

Religion has a fundamental influence in shaping treatment decisions at the end of life. ...The idea of autonomy, right to self determination and control over dying is not a universal value and it is not shared in all parts of the world. Many patients might prefer involvement in decision making by families and health professionals. The concept of advance care planning documents is not universally accepted and might be seen as an 'intrusive legal mechanism' interfering with the family responsibility to care for their loved ones, a violation of one's self identity and family. (11)

In some cultures where the patient is protected from hearing their diagnosis while the family receives the information, discussing advance care planning might actually harm patients and their families' (11).

The research evidence highlights that religion has a fundamental influence in shaping treatment decisions and this must be understood and respected by healthcare professionals when they need to consider advanced care planning and the application of CPR.

Sex

There is evidence to demonstrate that there is a gender difference in life expectancy and women in Wales can expect to live 4.4 years longer than men. Females are, however, estimated to spend only around two years longer than males in good health or free from limiting long-term illness or disability. (3)

There is no research evidence to suggest that there are particular issues that need highlighting in relation to DNACPR.

Sexual Orientation

Research identifies a number of key issues for LGB people: professional staff attitudes towards sexual identities influences the quality of care offered and received and that heterosexual assumptions may exist throughout care (12).

Consultation for the English End of Life Care Strategy Equality Impact Assessment noted that in terms of quality of end of life care, Lesbian, Gay and Bisexual (LGB) people were most at risk of discrimination (12).

Guidance produced by the Royal College of Nursing and UNISON (Not 'just' a friend: best practice guidance on healthcare for lesbian, gay and bisexual service users and their families) suggests that it can be a concern for LGB people that someone close to them will be denied visiting rights and information because they are not seen as the 'next of kin'. Guidance was published by the Welsh Assembly Government in 2008 to raise awareness of the needs and rights of lesbian, gay and bisexual people when accessing healthcare services in Wales (13).

The guidance highlights that recognition of next of kin/nominated contact when one partner is in hospital or needs medical treatment is an issue of great concern to same-sex partners.

Although there is no legal definition of 'next of kin' in this context, and nothing to prevent same-sex partners acting as 'next of kin'/nominated contact in these circumstances, there are still misconceptions about this among the general public and among medical and other staff. Confusion arises over who is 'next of kin' because the general understanding of the term is that it is a blood relative or married or civil partner. However, this is not the case and lesbian and gay couples who have not registered a civil partnership and unmarried heterosexual couples can, if they so wish, nominate their partner as 'next of kin'. (13)

The DNACPR Framework will need to ensure that it is inclusive of and recognises the rights of same-sex families. Medical and other staff should be supported to challenge prejudiced attitudes and behaviour in staff and other service users and need to be aware of the impact on privacy and confidentiality. The important need to recognise the diverse identities of patients and to be sensitive to their choice of 'next of kin' was raised throughout the engagement work.

Older lesbian, gay or bisexual people represent a generation who lived in times when same sex relationships were pathologised and, for gay and bisexual men, illegal. This group may have experienced incidences of prejudice and therefore be less open than younger generations. (12)

Research suggests that it is likely that older LGB people will anticipate or have had experience of negative reactions relating to their sexual orientation or gender identity. This can impact on the person's ability to have discussions about end of life care and access to local community support.

Previous disclosure of sexual orientation may have been traumatic. For some it could also lead to a distancing from families of origin such that the individual may rely on and prefer alternative networks of support. However, there is a risk that the significance of 'friend' relationships is not recognised before and after death. This could result in a person or group, their relationship with the dying person and their grief going unrecognised. (12)

Gender Re-assignment

The above research considered in the context of Lesbian, Gay and Bisexual people also included the experiences of Transgendered people. Many of the issues highlighted above will be as relevant to Transgendered people.

Welsh Language

Public services have a responsibility to comply with the new Welsh Language (Wales) Measure. This will create standards regarding Welsh which will result in rights being established that will ensure Welsh speakers can receive services in Welsh. Meeting the information and communication needs of patients who speak Welsh will need to be taken into account in the DNACPR decision making process.

'Language is at the core of establishing and expressing identity. Responding sensitively to language, whilst focusing on the individual, is an essential principle of maintaining dignity and respect in care within a bilingual setting'. (14)

Language provision is particularly important for older people who may only be able to communicate using their first language when they become unwell. The Strategic Framework for Welsh Language Services in Health, Social Services and Social Care, 'More than just words ...' refers to older people in residential care settings discovering 'that their 'sense of self' and 'social recognition' diminishes because their body and mind is deteriorating. Some will have already suffered losses such as bereavement, their home, and some physical and mental skills. It's essential therefore to provide care that reflects a person's language and cultural background in order to respect their identity and maintain their dignity'. (14) In addition to older people, the Welsh Government has identified three other priority groups where Welsh language services are especially important, these are: children and young people; people with learning disabilities and people with mental health problems. These groups are particularly vulnerable because their care and treatment suffers when they are not treated in their own language.

Human Rights

A CPR decision is highly relevant to the Human Rights Act 1998 and in particular, the right to life (Article 2), the right not to be tortured or treated in an inhuman or degrading way (Article 3) and the right to respect for private and family life, home and correspondence (Article 8).

Clinical decisions about whether or not to attempt CPR often arise in difficult circumstances. Rates of survival and complete physiological recovery following in-hospital cardiac arrest are poor. A high proportion of in-hospital deaths now involve CPR attempts, even when the underlying condition and general health of the patient makes success very unlikely. This can mean that patients may undergo futile attempts at CPR during their dying process. Effective Do Not Attempt (DNA) CPR decision making should improve patient care and prevent futile and undignified procedures at the end of life.

Research published by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD 2012) (1) revealed the need for a closer definition of the aims of the treatment of sick people in hospitals and raises many issues including the disparity between the public and professional perception of the outcome of CPR, effective communication and informed consent and ensuring a dignified death.

There are times when cardiopulmonary resuscitation (CPR) is inappropriate. It may be futile because a patient is dying from a terminal illness or it may be against the wishes of the patient. A decision making process that allows healthcare professionals to be informed when CPR should not be initiated, is central to person centred care and enabling a dignified death for patients and compassion for their families and carers who would want their loved one's wishes to be fulfilled.

Placing DNR notices on a patient's record without their knowledge or consent or that of their family members is likely to constitute a breach of human rights and in particular, Article 8 which safeguards respect for patients' private lives. The Equality and Human Rights Commission intervened in a Court of Appeal case which revolved around whether seriously ill patients and their loved ones have the right to be consulted about the use of DNR Notices. The Court of Appeal has ruled that doctors have a legal duty to consult with and inform patients if they want to place a DNR order on medical notes.

Historically, blanket policies that are based on subjective factors such as age and quality of life may also have a discriminatory impact and could be subject to a human rights challenge.

4. Themes from Engagement

The third sector organisations that have been involved in the DNACPR engagement work are listed on Appendix 1. The key themes that were highlighted through engagement are:

- The important need to ensure that patients and carers/families are fully involved in the DNACPR decision making process.
- The need to ensure that the appropriate next of kin is recognised in the care and treatment of an individual.
- The need for effective, accessible and kind and sensitive communication and information to ensure that DNACPR is explained and understood. Good communication is at the heart of this. It is about communication between families and not just professionals. People knowing what their loved one would want.
- The need to ensure that DNACPR decisions are recorded and transferred across and between primary, community, secondary and independent care sector organisations.
- The need to promote a non judgemental and positive attitude towards disabled and older people to ensure that DNACPR decisions are not based on unlawful discriminatory attitudes and stereotypes.
- The need to inform and change public perceptions of CPR and the limits of its effectiveness.

- The need to address the risk of creating negative perceptions of DNACPR decisions as a withdrawal of any further treatment and care.
- Mental health is not the same as mental capacity. It is important to recognise symptoms and their impact on mental capacity. The timing of conversations to explore an individual's wishes is important in this respect. A decision may reflect the way the person is feeling at that particular time.
- Part of the Policy should be about who has the conversation

 senior medical staff, the person who knows the patient, their illness and prognosis.
- Faith, culture and end of life.
- Welsh Language and other language provision.
- This is not just about older people. It is about everyone.
- The role and involvement of carers and people without carers/family or estranged families and homeless people the role of independent advocacy.
- People receiving healthcare outside of Wales, for example, prisoners in England and people with severe mental illness cross border issues.
- Family/carer support and the issue of guilt.
- The need for simple information for all ages.
- The application of electronic record systems and processes for information travelling with patient. How will the Policy work in emergency situations and how will information transfer between primary, secondary, community and independent care settings.
- How will accountability be addressed within the Policy Framework, including how you ensure that everyone is

responsible for implementing the Framework, that staff are familiar with and have been trained in the process and the standards expected as well as receiving training in communication skills, plus the need to understand that they will be held to account for their actions.

 How will the Policy Framework be monitored and will the process be self assessment. If this is the proposed tool for the framework, it might be helpful to acknowledge that this might not give a true assessment of the situation. Self assessment can be successful where there is a genuine desire to improve but it can also have the potential to mask poor performance when there is denial that improvement is needed. An example of this is the Mid Staffs Healthcare Commission report which showed that the hospital was functioning well, whilst in actual fact it was failing.

There could be cross referencing the results with complaints received/concerns raised in relation to DNR decisions, HIW and Ombudsman complaints/investigations, etc. It might be useful to look at other all Wales Frameworks that have been introduced, eg nutrition/medicines, to assess the effectiveness of the monitoring tool and any improvements to enhance it.

It might be useful to consider whether an external assessment could help with raising the credibility of the audit process. Patient stories could be used in conjunction with other methods, for example, inviting people who have used the service to work alongside professionals. This could include involving people in staff interviews and induction, audit meetings, research, resolving complaints, concerns, etc

The main themes highlighted are that communication has to be at the core of the policy and practice; that DNR decisions must be grounded in person centred care that acknowledges and responds to the diverse needs and identities of patients and that robust and transparent monitoring arrangements are developed and implemented that are capable of evidencing that the Policy is being delivered effectively.

5. Outcomes

Equality impact assessment is a continuous process. The assessment has so far demonstrated that DNACPR is relevant to all of the protected characteristics and that there are particular issues to consider with regard to age, disability, race, sexual orientation and human rights. Research has evidenced that there is the potential for DNACPR decisions to impact adversely on disabled and older people. This will need to be monitored as part of the implementation of the policy at a local level to ensure that there is no negative impact.

There is a lack of research specific to Wales to highlight the issues and/or experiences of Lesbian, Gay, Bisexual and Transgendered people, older Black Minority Ethnic (BME) groups and different faith groups. Focused engagement with these groups at a national and local level should be explored as the Policy is further developed and monitored.

The important need to involve carers and people who are close to the patient in the DNACPR decision making process is recognised within the policy framework. Developing awareness of the Policy with carers and organisations that represent them should help to ensure that the aims of the Policy in this respect are achieved.

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Appendix 1

A Dignified Revolution

Age Cymru

Diverse Cymru

Gofal Cymru

Marie Curie

Mencap Cymru

Older People's Commission

Transgendered Wales