Advance Care Planning Policy
**Executive Summary:**
East Cheshire NHS Trust is committed to supporting and enabling health and social care professionals to recognise and respond effectively to adults requiring Advance Care Planning (ACP). This may include people living with life-limiting illness or frailty, those at or approaching the end of life, as well as those people who may choose to make plans for their future care and/or treatment. Effective use of ACP can support people to plan ahead where possible and therefore increases the likelihood that a person's preferences and wishes will be considered and where practical these will be met, even when they are no longer able to express them.

**Supersedes:**
Version 1

**Description of Amendment(s):**

**This policy will impact on:**
- Heads of service
- Consultants and clinical teams
- Trust Cancer Lead
- Lead Cancer Nurse

**Financial Implications:**
All trust clinical staff

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East Cheshire NHS Trust – Advance Care Planning Policy

1. POLICY STATEMENT

1.1 East Cheshire NHS Trust are committed to supporting and enabling health and social care professionals to recognise and respond effectively to adults requiring advance care planning (ACP). This may include:
- People living with life-limiting illness or frailty
- People at or approaching the end of life
- People who may choose to make plans for their future care and/or treatment

1.2 Effective use of ACP can support people to plan ahead where possible and therefore increases the likelihood that a person’s preferences and wishes will be considered and where practical these will be met, even when they are no longer able to express them.

1.3 This policy sets out the principles behind ACP which can be defined as: a voluntary process of discussion between an individual, their care providers and often those close to them, about their future care and wishes.

1.4 Preferences for care may be expressed in the form of an Advance Statement of Wishes, an Advance Decision to Refuse Treatment (ADRT), or may be stated in the future by a person who has been given Lasting Power of Attorney (LPA) for Health & Welfare for a person who no longer has the capacity to express their wishes.

1.5 Relevant aspects of the Mental Capacity Act (MCA) 2005 are also highlighted in this policy although health and social care professionals will be expected to have a good working knowledge of the MCA in order to effectively apply the principles of ACP.

2. ORGANISATIONAL RESPONSIBILITIES

2.1 Manager Responsibilities
- Ensure employees are aware of the content of this policy and its implementation.
- Ensure ACP knowledge and skills are considered as part of annual appraisal.

2.2 Employee Responsibilities
- Be aware of and follow the principles of ACP set out within this policy when discussing future care with people involved in your care, as well as when documenting and communicating the outcomes of these discussions.
- Delegation to specialist colleague where appropriate.
- Seek legal advice where implicated.
- Access ACP training in accordance with minimum standards defined by East Cheshire NHS trust and in line with personal learning objectives/ongoing professional development.

2.3 Legal Department
- Provide support and guidance on relevant legislation and application of this policy.
3 ACP PRINCIPLES

3.1 ACP is a voluntary process of discussion between an individual, their care providers and often those close to them, about future care and wishes.

3.2 People accessing East Cheshire NHS trust services should be provided with opportunities to discuss and outline their wishes and priorities for their future, but not feel pressured into discussions they are not ready to have.

3.3 Health and Social Care professionals should consider initiating ACP discussions when caring for those with a life-limiting or life-threatening illness or frailty, and also with those who are on the Gold Standards Framework/Palliative Care Register, therefore indicating that the professional would not be surprised if the person died within the next year. Opportunities’ for ACP discussions may also arise when talking with people who are not thought to be at risk of deterioration but who choose to express concerns or opinions about their future care.

3.4 ACP discussions should not be rushed and often take place on more than one occasion, over a period of time.

3.5 Individuals may feel that discussing their future care issues is sufficient, in which case seeking their permission to share the outcomes of such discussions with others involved in their care should be considered as best practice. An individual may also wish to document their preferences and wishes in the form of an Advance Statement of Wishes or an Advance Decision to Refuse Treatment (ADRT).

3.6 An Advance Statement of Wishes is not legally binding but can be useful for documenting general statements about preferences and wishes. The template that East Cheshire NHS trust uses for recording a person’s Advance Statement of Wishes can be found in Appendix A.

3.7 An ADRT only applies to refusal of treatment, is legally binding, providing it is valid and applicable to the presenting circumstances, and should therefore be as specific as possible, relating to potential clinical scenarios. The template that East Cheshire NHS trust uses for recording an ADRT can be found in Appendix B.

3.8 Documentation relating to ACP should be reviewed regularly with the individual, e.g. every 6 months, or sooner if there is a change in the their condition or a significant event e.g. hospital admission or change in treatment goals.

3.9 Permission should be sought to share ACP documentation including the outcomes of informal ACP conversations with relevant Health and Social Care providers including the ambulance and out of hours services.

3.10 The use of Electronic Palliative Care Coordination Systems (EPaCCS) is one way to share information about a person’s wishes and preferences with other services involved in their care. Further information about the use of EPaCCS within East Cheshire NHS trust can be found in EMIS web.

3.11 A person can legally appoint someone as an attorney to make decisions at a time in the future when he/she no longer has capacity, by registering a Lasting Power of Attorney (LPA) document with the Office of Public Guardian. There are two types of LPA: (1) Property and Financial Affairs, and (2) Health and Welfare. Only holders of an LPA for health and welfare have authority to make healthcare decisions.
3.12 For those who lack capacity, and do not have an ADRT or LPA, ‘best interests’ decisions relating to healthcare should be made by their medical team, having consulted with people who are engaged in caring for them or interested in their welfare. For those who have no-one to represent their views or wishes, an independent mental capacity advocate (IMCA) should be appointed.

4. POLICY

Introduction

4.1 The policy aims to provide a structure for the management of people requiring support with any aspect of ACP across all organisations within the End of Life Partnership. The policy aims to support Health and Social Care professionals in the following areas:

- Understanding the legal issues surrounding ACP
- Initiating the ACP process and supporting those we care for to communicate and to document their wishes, including where appropriate, completion of an Advance Statement of Wishes, or Advance Decision to Refuse Treatment
- Informing individuals of the purpose and process for making a Lasting Power of Attorney
- Accessing appropriate training and resources to support the process of ACP
- Decision making for patients without capacity, including assessment of capacity, and the use of Independent Mental Capacity Advocates

The Advance Care Planning Process

Initiating an ACP Discussion

4.2 The End of Life Care Strategy in 2008 emphasised the importance of providing the opportunity for those with life-limiting illness to discuss their wishes and priorities for their future care. Since then, other national initiatives have aimed to place the individual at the centre in decisions and plans for their future care.

4.3 Health and Social Care professionals should consider initiating a discussion about the concept of ACP when involved in the care of a person with any of the following:

- Those with a life-limiting or life-threatening illness
- Those with a long term condition, e.g. dementia, multiple sclerosis, etc., where the prognosis may be years, but capacity and/or communication is likely to be lost well before the end of life phase
- Those receiving end of life care
- Those on the Gold Standards Framework/Palliative Care Register for whom the health care professional would not be surprised if the person died within the next year
- Those who choose to express concerns / opinions about their future care

4.4 ACP discussions can be led by any Health or Social Care Professional that is involved in the persons care. This is most likely to be a Doctor, Social Worker or Nurse. Such discussions should be undertaken by someone with the necessary expertise and knowledge base, and who has a rapport with the person. This person should have adequate knowledge of the disease, treatment and the individual to be able to give them all the information needed to express their preferences. It may therefore be necessary to obtain input from other colleagues including the palliative care team members or hospital specialists, to ensure that the patient has adequate relevant clinical information.

4.5 Ideally, ACP discussions should be initiated by the professional who knows the person best and at a point before they become clinically unstable, though this is not always possible. It is advisable that where possible discussions should not be initiated immediately at the point a person is admitted to a new care setting e.g. to a care home, as this can cause additional
anxiety often at a time of uncertainty and change. In addition to this a recent significant diagnosis may cause subsequent anxiety and/or depression which could result in a hastily drafted document. This possibility should be considered by the Health or Social Care professional leading the discussion and explored with the patient where felt appropriate.

4.6 The topic of ACP should be introduced to the person in a timely and sensitive way with opportunity given for the person to choose whether this is something that he/she would like to explore further. If so, the patient may find the following written information to be helpful:

Website: NHS Choices Planning Ahead for End of Life
Leaflet: Planning for your Future Care

4.7 Professionals should take account of the following factors that may influence attitudes to discussing ACP, and ensure that these factors do not act as a barrier to discussion:

- Some people may be concerned about the burden of their illness on their family
- The individual’s gender, race, culture, sexual orientation, religion, beliefs and values
- The individual’s concerns about euthanasia
- The professional’s own beliefs and experience. It is important that these views do not influence the direction of the conversation with the individual

4.8 At an agreed time, the Health or Social Care professional should meet with the individual (and someone close to them if this is what he/she wants) to discuss their wishes for the future. Such discussions can become lengthy, so adequate time should be allowed. Discussions should not be rushed and often need to take place on more than one occasion (over days, weeks, months). In addition they cannot be completed as a simple checklist exercise.

4.9 The person should be assumed to have capacity to make decisions. If there is any doubt, then capacity to make a specific decision should be tested - see section 8.

4.10 It is important that the person has maximal opportunity to participate in the discussion and that any condition that affects communication, such as hearing loss, is accommodated for in order to facilitate this.

4.11 A step-by-step approach should be used which may be guided by the algorithm provided in Appendix C. Discussions should be characterised by honesty, respect, time, compassion and empathy. Once started the professional should look out for cues that the individual wishes to end the discussion as it should not be continued if it is causing excessive distress or anxiety.

4.12 Clarity is essential – information should be explained in words that the person understands, and ambiguous terms used by the individual (for example ‘heroics’) clarified. It is essential that the person understands the decisions he/she is making, their consequences and the circumstances under which they would be activated. Any unrealistic expectations, and/or conditional factors that are likely to affect the achievement of their wishes should be explored sensitively.

4.13 The person should be encouraged to discuss ACP with other relevant health care professionals. Although not a legal requirement, it is particularly important that ADRTs should be discussed with a doctor.

Outcomes of ACP Discussions.
4.14 The initiation of an ACP conversation may lead to any of the following outcomes:

- The individual deciding that he/she does not want to pursue such a discussion at this time.
• The individual expressing his/her wishes verbally to those close to him/her which may or may not include giving permission for the their wishes to be shared with other Health and Social Care Professionals e.g. via EPaCCS
• The individual documenting his/her priorities in an Advance Statement of Wishes (section 5)
• The individual making an Advance Decision to Refuse Treatment (ADRT) (section 6)
• The individual submitting a Lasting Power of Attorney for Health and Welfare with the Office of Public Guardian (section 7)

Documenting ACP Discussions
4.15 If the individual is happy for their preferences and wishes to be formally recorded, the professional should summarise the discussion, check the person’s understanding, and support them to document their wishes using an Advance Statement of Wishes (Appendix A), or an ADRT (Appendix B). The algorithm in Appendix C will assist in identifying which of these documents is most appropriate.

4.16 It may be that the individual does not want to document their wishes, but to nominate someone to make health care related decisions for them, should they in the future lose capacity to make these decisions for themselves. This would require them to register a Lasting Power of Attorney (LPA) document with the Office of Public Guardian – see section 7

4.17 The outcomes of ACP discussions should be recorded within the persons care records and permission should be sought to share this information with other professionals involved in their care. It is best practice to share details with those who have medical responsibility for the person i.e. the persons General Practitioner and/or Hospital Consultant.

4.18 Where applicable details of ACP conversations and documentation should be recorded electronically using the EPaCCS template

4.19 Where appropriate, the person should be informed that:
• Documenting his/her wishes in an advance statement does not guarantee that their wishes will be respected, but a valid ADRT must be followed.
• Health care providers are not obliged to provide medical care if it is inappropriate
• ADRTs are not valid if an LPA covering the same treatment was appointed after the ADRT was made

4.20 The Person should be advised to keep their Advance Statement/ ADRT in a safe place at home and to notify others including family members about how it can be accessed. For those living in their own home it is advisable that documentation is kept at the front of any other care related notes that are kept within the home.

Review of ACP Documentation
4.21 The ACP discussion/documentation should usually be reviewed every 6 months. However, if the person’s health status changes, there is a new diagnosis, or if there is a significant change in their circumstances, the documentation needs to be reviewed at that time. Keeping a circulation list with the patient’s copy is recommended to ensure updates go to all relevant people.
5. **Advance Statement of Wishes**

5.1 In many cases individuals are satisfied with a discussion about their wishes and priorities with their loved ones and with those involved in their care, and do not want to document these discussions.

5.2 For those who do wish to document their views and priorities about future care, an Advance Statement of Wishes can be drawn up and subsequently be used to guide Health and Social Care professionals in the future. The template within Appendix A is recommended for use when a person wishes to make a generalised statement about what is important to them in relation to their future care. An Advance Statement of Wishes should not be used in instances where the person wants to refuse treatment- this would require an ADRT (see section 6).

5.3 An Advance Statement of Wishes is NOT legally binding. However information contained within it may be used to inform 'a best interest decision' should a person lose capacity.

5.4 The master document should be kept by the person, and with their agreement, further copies filed prominently in medical and/or other care notes and shared with other relevant professionals involved in the persons care.

6. **Advance Decisions to Refuse Treatment**

**Definition and application of an ADRT**

6.2 An ADRT is a written statement that legally allows a person to refuse specific treatment(s) should they occur in a predefined potential future situation.

6.3 The Mental Capacity Act 2005 sets out the requirements of an ADRT in order for it to be valid and applicable:

- The ADRT must be in writing
- The ADRT must be signed by the person or by another person in the person’s presence and by the person’s direction
- The person’s signature must be made or acknowledged in the presence of a witness
- The witness must sign the ADRT in the person’s presence
- The ADRT must be dated

6.4 An ADRT can only be made by a person aged 18 years or above while they still have capacity, and only becomes active when they lose capacity.

6.5 An ADRT only applies to a refusal of treatment and cannot be used to request treatment and/or refuse basic care.

6.6 An ADRT is **invalid** if:

- The person withdrew the ADRT while they still had capacity
- After making the ADRT, the person made a LPA, giving authority to an attorney to make treatment decisions that are the same as covered within the ADRT
- The person has done something that clearly goes against the ADRT, suggesting that they have changed their mind.
- The proposed treatment is not the treatment specified within the ADRT
- The circumstances are different from those that have been set out in the ADRT
- There are reasonable grounds to believe that there have been changes in circumstances which would have affected the decision of the person had he/she known about them at the time of making the ADRT
6.7 If the ADRT is not valid or applicable in the current circumstances, the professional must consider the ADRT as part of their assessment of the person’s best interests (see section 8)

Making an ADRT

6.8 At the end of ACP discussions, a person may decide that he/she wants to refuse a specific treatment in which case they should be supported to make an ADRT. Although not legally necessary, it is good practice for a Doctor with medical responsibility for the patient to be consulted with in the process of making an ADRT

6.9 If there is any doubt about the mental capacity of the patient, the professional should make a formal assessment of capacity. If needed, a second opinion should be sought before proceeding with the ADRT. The professional should document that the patient has capacity when making the ADRT in their case notes

6.10 The professional must ensure that all potential scenarios that are relevant to the person’s clinical condition are discussed, and that the person understands the consequences of the decisions he/she is making. It is important that the ADRT is specific about the medical care that a person wishes to refuse. This may require seeking support/input from other colleagues to ensure that this is achieved.

6.11 The healthcare professional should consider discussing the following interventions with the person, depending on their condition and likely mode of deterioration:

- Use of antibiotics (e.g. route of administration, escalation to use second-line antibiotics, place of administration - home/hospital etc.)
- Use of artificial feeding – enteral (nasogastric or PEG), parenteral (TPN)
- Use of artificial hydration – enteral (nasogastric or PEG), parenteral (intravenous, subcutaneous)
- Use of cardiopulmonary resuscitation
- Use of artificial ventilation – non-invasive, invasive
- Use of dialysis
- Use of blood products
- Use of surgery
- Use of urinary catheterisation

6.12 The person should be encouraged to discuss the ADRT with his/her doctor (both GP and specialist) before it is finalised

6.13 The document in Appendix B – an Advance Decision to Refuse Treatment – is recommended and should be completed by the person with assistance from the professional – it may be appropriate for the professional to draft an ADRT on behalf of the person after an initial discussion and then to finalise it on a subsequent meeting.

6.14 The ADRT should be signed, witnessed, dated and a review date set. It must clearly state the words ‘even if my life is at risk’ against all refusals
Communication of an ADRT

6.15 A copy of the document should be kept by the individual, and with their agreement, further copies filed prominently in their hospital and GP held medical notes.

6.16 If the person has an EPaCCS record, reference to the ADRT should be made within this so that it is clearly evident that such a document exists and should be followed if the circumstances apply.

6.17 When the ADRT is reviewed and/or amended, updated versions must be distributed to all relevant health care professionals. Keeping a circulation list with the patient’s copy is recommended to ensure updates go to all relevant people.

7. Lasting Power of Attorney for Health & Welfare

7.1 At the end of ACP discussions, a person may decide that they would like to make a Lasting Power of Attorney (LPA). This is a legal document that allows him/her to appoint someone as an ‘attorney’ to make decisions at a time in the future when he/she no longer has capacity. There are two types of LPA:

- property and financial affairs, or
- health and welfare

7.2 Holders of LPA for Property and Affairs have no authority to make health and welfare decisions, but should be consulted as part of the best interests determination.

7.3 An LPA can only be made by someone who:

- is over 18 years of age, and
- has capacity

7.4 An LPA can only be used after it has been registered with the Office of Public Guardian. This process can take up to eight weeks.

7.5 If a person indicates that he/she would like to make an LPA, he/she should be directed to the Office of Public Guardian enquiry line (0300 456 0300) or to the guidance notes available online: (http://www.publicguardian.gov.uk/arrangements/lpa.htm). The document specifies who is appointed as the person’s attorney and provides space for him/her to express any specific wishes to guide the attorney.

7.6 All relevant professionals should be informed that a person has made an LPA and given the contact details of the Attorney.

7.7 Health care professionals should confirm with the Office of Public Guardian that a person has made an LPA and check its contents before consulting the Attorney about Health & Welfare decisions. If someone claims to be an LPA then professionals should ask to see the relevant documentation.

8. LPA’s for Health & Welfare may or may not have been delegated authority to refuse life sustaining treatment of behalf of the person. This will be detailed in Part A or Part B of the LPA official documentation. If there is any uncertainty professionals should seek the advice of the Trust Legal Services via email: ecn-tr.legalservices@nhs.net or by telephone on 1768 or 1332.

9. Mental Capacity & ACP (please in conjunction with Mental Capacity Act 2005 Policy)
Assessment of Capacity

8.1 Health and Social Care professionals should assume that an individual has capacity – the ability to make their own decisions. However, if he/she has an impairment or disturbance of the functioning of the mind/brain that may affect his/her ability to make a specific decision, capacity should be assessed. This is tested as followed:

1. Can they understand the information?
2. Can they retain the information?
   NB: This should only be for long enough to use and weigh up the decision.
3. Can they use or weigh up the information, including understanding the consequences of their decision?
   NB: They must be able to demonstrate that they are able to consider the benefits and burdens of the alternatives to the proposed treatment.
4. Can they communicate their decision?

8.2 Any assessment of capacity has to be made in relation to a particular treatment choice.

8.3 A person’s capacity can vary over time, so professionals should identify the time and method most suitable for the individual to discuss treatment options. It may be necessary to call on an expert to make an assessment of the person’s capacity if proving difficult to ascertain. In addition a person may have capacity for simpler decisions about their future care but not for more complex ACP decisions.

8.4 All assessments of a person’s capacity should be documented in the persons clinical records along with details about the method by which the assessment was undertaken.

8.5 It is good practice, particularly in complex situations, for more than one professional to assess and determine a person’s capacity. However, the final responsibility remains with the senior doctor caring for the patient.

8.6 If the person has capacity, he/she can make the relevant decision.

Making Care Decisions when a person lacks capacity

8.7 If the person does not have capacity, the professional should ascertain whether the individual has a valid ADRT or a health and welfare LPA that will guide the approach to treatment:

- If an ADRT is the most recent decision, check whether the current circumstances match those specified within the ADRT and that the ADRT is valid (see sections 6.2-6.7) If this is the case, the decisions within the ADRT should be followed.
- If the appointment of a Health and Welfare LPA is the most recent decision, check that the LPA has been registered with the Office of Public Guardian, and that it includes the authority to decide on serious medical conditions, fully inform the LPA of the clinical facts and ask the LPA for their decision. NB: the ’best interests’ framework still applies (see section 8)

8.8 If there is no ADRT or LPA, the patient does not have capacity and the person does have someone who can be consulted about their best interests, a decision-maker should be appointed. A decision-maker is the person who has the responsibility to decide what is in the best interests of the person who lacks capacity. For most day-to-day decisions, the decision-maker will be the care provider most directly involved with the person at that time. Where the decision involves the provision of medical treatment, the doctor or other health care professional responsible for carrying out the procedure/treatment is the decision-maker. In many cases, including decisions about end-of-life care, consultation with all the health and
social care professionals involved in a person’s care is ideal to ensure that a decision that is in the person’s best interest is reached.

8.9 If there is no ADRT or LPA, the person does not have capacity, and the person does not have anyone who can be consulted about their best interests (see section 8), appropriate care and treatment should be administered in an emergency and in accordance with their ‘best interests. Following this ‘emergency period’ and as soon as it practically possible an Independent Mental Capacity Advocate (IMCA) should be involved (see section 8)

**Best Interests**

8.10 A person’s care should always be aimed at their best interests. Best interests assessment includes a requirement to consider, so far as can be reasonably ascertained a person’s past and present wishes and feelings (including any written Advance Statement of Wishes made while the person had capacity), beliefs and values, any other factors that the person would consider important in determining their wishes. The views of whoever is important to the individual engaged in caring for them or interested in their welfare should also be considered.

8.11 A decision-maker should make a best interests decision by:

- Encouraging participation of the individual concerned
- Identifying all relevant circumstances
- Finding out views that the person may have expressed verbally or within an Advance Statement of Wishes /ADRT made when the person had capacity
- Consulting others (within the limits of confidentiality) – family/friends/carers etc
- Avoiding discrimination or making assumptions about the person’s quality of life
- Assessing whether the person might regain capacity
- Avoiding restricting the person’s rights
- Ensuring that, if the decision is about life-sustaining treatment, a decision is not motivated by a desire to bring about the person’s death.

**Independent Mental Capacity Advocate (IMCA)**

8.12 An Independent Mental Capacity Advocate (IMCA) is appointed to represent a person who lacks capacity and has no-one else to represent them, at a time when important decisions about medical treatment, change of accommodation, care reviews or adult protection procedures are being made.

8.13 When a decision is being made for a person who lacks capacity, Health and Social Care professionals should consult with the family and friends of the person to see whether there is anyone who is prepared to be consulted about the decision to be made. If it is not possible, practical or appropriate to consult someone known to the person, an IMCA should be instructed.

8.14 For those who are receiving care at East Cheshire NHS trust an IMCA can be instructed by contacting the Cheshire Advocacy Hub. For contact detail see Appendix D.

8.15 Once appointed the IMCA will:

- Establish the referred person’s preferred method of communication
- Meet with the referred person and use a variety of methods, as appropriate to ascertain their views
- Consult with professionals and anyone else who knows the person well who are involved in delivering their care, support and treatment
- Gather any relevant documents and information
• Attend meetings to represent the person raising issues and questions as appropriate
• Present information to the decision-maker verbally and via a written report
• Remain involved until the decision has been made
• Audit the best interests decision making process
• Challenge the decision if necessary

8.16 An IMCA cannot be involved if:
• The person has capacity
• The proposed treatment is authorised under the Mental Health Act 1983 and is therefore for a mental disorder rather than a physical condition
• The proposed change in accommodation is a requirement under the Mental Health Act 1983
• There is no identifiable decision to be made
• There is another person (not in a paid capacity) who is willing and able to support and represent appropriately the person who lacks capacity
• Decisions are being made in relation to the person’s finances

Further information about the IMCA service can be found at: http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/making-decisions-opg606-1207.pdf

10. ACP Training & Resources

Clinical staff can access e-learning via the Cheshire epaige. Face to face sessions are also provided by the end of life partnership.

11. Monitoring Compliance & Effectiveness
The monitoring of compliance and effectiveness of advanced care planning at East Cheshire NHS Trust will be done via an annual audit and presented to professional forum in conjunction with the end of life partnership.
12. Equality Impact Assessment

1. What is being assessed?

Advanced Care planning policy

Details of person responsible for completing the assessment:

- Joanne Humphreys
- Lead cancer Nurse
- Cancer Services

State main purpose or aim of the policy, procedure, proposal, strategy or service:

East Cheshire NHS Trust is committed to supporting and enabling health and social care professionals to recognise and respond effectively to adults requiring Advance Care Planning (ACP). This may include people living with life-limiting illness or frailty, those at or approaching the end of life, as well as those people who may choose to make plans for their future care and/or treatment. Effective use of ACP can support people to plan ahead where possible and therefore increases the likelihood that a person’s preferences and wishes will be considered and where practical these will be met, even when they are no longer able to express them.

2. Consideration of Data and Research

To carry out the equality analysis you will need to consider information about the people who use the service and the staff that provide it.

2.1 Give details of RELEVANT information available that gives you an understanding of who will be affected by this document

Cheshire East (CE) covers East Cheshire CCG. Cheshire West & Chester (CWAC) covers Vale Royal. In 2011, 370,100 people resided in CE and 329,608 people resided in CWAC.

Age: East Cheshire and South Cheshire CCG’s serve a predominantly older population than the national average, with 19.3% aged over 65 (71,400 people) and 2.6% aged over 85 (9,700 people).

Vale Royal CCGs registered population in general has a younger age profile compared to the CWAC average, with 14% aged over 65 (14,561 people) and 2% aged over 85 (2,111 people).

Since the 2001 census the number of over 65s has increased by 26% compared with 20% nationally. The number of over 85s has increased by 35% compared with 24% nationally.

Race:
- In 2011, 93.6% of CE residents, and 94.7% of CWAC residents were White British
- 5.1% of CE residents, and 4.9% of CWAC residents were born outside the UK – Poland and India being the most common
- 3% of CE households have members for whom English is not the main language (11,103 people) and 1.2% of CWAC households have no people for whom English is their main language.

**Gender:** In 2011, c. 49% of the population in both CE and CWAC were male and 51% female. For CE, the assumption from national figures is that 20 per 100,000 are likely to be transgender and for CWAC, 1,500 transgender people will be living in the CWAC area.

**Disability:**
- In 2011, 7.9% of the population in CE and 8.7% in CWAC had a long term health problem or disability
- In CE, there are c.4500 people aged 65+ with dementia, and c.1430 aged 65+ with dementia in CWAC. 1 in 20 people over 65 has a form of dementia
- Over 10 million (c. 1 in 6) people in the UK have a degree of hearing impairment or deafness.
- C. 2 million people in the UK have visual impairment, of these around 365,000 are registered as blind or partially sighted.
- In CE, it is estimated that around 7000 people have learning disabilities and 6500 people in CWAC.
- Mental health – 1 in 4 will have mental health problems at some time in their lives.

**Sexual Orientation:**
- CE - In 2011, the lesbian, gay, bisexual and transgender (LGBT) population in CE was estimated at 18,700, based on assumptions that 5-7% of the population are likely to be lesbian, gay or bisexual and 20 per 100,000 are likely to be transgender (The Lesbian & Gay Foundation).
- CWAC - In 2011, the LGBT population in CWAC is unknown, but in 2010 there were c. 20,000 LGB people in the area and as many as 1,500 transgender people residing in CWAC.

**Religion/Belief:**
The proportion of CE people classing themselves as Christian has fallen from 80.3% in 2001 to 68.9% in 2011 and in CWAC a similar picture from 80.7% to 70.1%, the proportion saying they had no religion doubled in both areas from around 11%-22%.
- **Christian:** 68.9% of Cheshire East and 70.1% of Cheshire West & Chester
- **Sikh:** 0.07% of Cheshire East and 0.1% of Cheshire West & Chester
- **Buddhist:** 0.24% of Cheshire East and 0.2% of Cheshire West & Chester
- **Hindu:** 0.36% of Cheshire East and 0.2% of Cheshire West & Chester
- **Jewish:** 0.16% of Cheshire East and 0.1% of Cheshire West & Chester
- **Muslim:** 0.66% of Cheshire East and 0.5% of Cheshire West & Chester
- **Other:** 0.29% of Cheshire East and 0.3% of Cheshire West & Chester
- **None:** 22.69% of Cheshire East and 22.0% of Cheshire West & Chester
- **Not stated:** 6.66% of Cheshire East and 6.5% of Cheshire West & Chester

**Carers:** In 2011, nearly 11% (40,000) of the population in CE are unpaid carers and just over 11% (37,000) of the population in CWAC.

2.2 Evidence of complaints on grounds of discrimination: (Are there any complaints or concerns raised either from patients or staff (grievance) relating to the policy, procedure, proposal, strategy or service or its effects on different groups?)
2.3 Does the information gathered from 2.1 – 2.3 indicate any negative impact as a result of this document?

No

3. Assessment of Impact

Now that you have looked at the purpose, etc. of the policy, procedure, proposal, strategy or service (part 1) and looked at the data and research you have (part 2), this section asks you to assess the impact of the policy, procedure, proposal, strategy or service on each of the strands listed below.

RACE:
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, racial groups differently? No

Explain your response: The use of ACP will be available to all races, where English is not the patient’s first language, staff will follow the trust interpretation policy and will provide any written information in the appropriate language and format.

GENDER (INCLUDING TRANSGENDER):
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, different gender groups differently? No

Explain your response: The use of ACP will be available to all genders, no impact identified.

DISABILITY
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, disabled people differently? No

Explain your response: The use of ACP will be available to people with disabilities. Staff will follow the trust interpretation policy where required and can provide information in a variety of formats in line with the Accessible Information Standard 2016. Where appropriate communication tools will be used to aid discussion such as the hospital communication booklet for people with limited communication. Carers and support workers will be involved as required to support the patient’s understanding of the issues and to aid communication with staff to best understand their wishes. If staff are unsure about a patient’s capacity a capacity assessment should be carried out – refer to trust Mental Capacity Act policy. Within the policy is detail on how to support people who may have difficulty communicating or who may lack capacity. The policy guides the reader through capacity assessment,. Best interests, IMCA appointment etc. with appropriate referral forms and documentation available. the form for application for an IMCA where it is found that a person lacks capacity and is unfriended.

AGE:
From the evidence available does the policy, procedure, proposal, strategy or service, affect, or have the potential to affect, age groups differently? No
Explain your response:

Age has no bearing on the use of ACP

**LESBIAN, GAY, BISEXUAL:**
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, lesbian, gay or bisexual groups differently?  No

**Explain your response:** Sexuality has no bearing on ACP, same sex partners would be involved as the patient wished in the same way as heterosexual partners.

**RELIGION/BELIEF:**
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, religious belief groups differently?  No

**Explain your response:** People with all religious beliefs will be offered discussions around ACP if indicated. Staff will be aware of religious/spiritual requirements and have access to 'Opening the spiritual gate' training and website. There is a form in the policy where patients are able to consent to refuse treatment in advance. Jehovah's Witnesses would also be able to use this form.

**CARERS:**
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, carers differently?  No

**Explain your response:** Where appropriate carers will be included in ACP discussions – see above sections.

**OTHER:** EG Pregnant women, people in civil partnerships, human rights issues.
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect any other groups differently?  No

**Explain your response:**

4. Safeguarding Assessment - CHILDREN

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Is there a direct or indirect impact upon children?</td>
<td>No</td>
</tr>
<tr>
<td>b. If yes please describe the nature and level of the impact (consideration to be given to all children; children in a specific group or area, or individual children. As well as consideration of impact now or in the future; competing / conflicting impact between different groups of children and young people:</td>
<td></td>
</tr>
<tr>
<td>c. If no please describe why there is considered to be no impact / significant impact on children</td>
<td></td>
</tr>
</tbody>
</table>

5. Relevant consultation

*Having identified key groups, how have you consulted with them to find out their views and that the made sure that the policy, procedure, proposal, strategy or service will affect them in the way that you intend? Have you spoken to staff groups, charities, national organisations etc?*
Policy written in co-ordination with East Cheshire Hospice and the End of Life Partnership Advice from the legal team sought.

6. Date completed: July 2017 Review Date: July 2019

7. Any actions identified: Have you identified any work which you will need to do in the future to ensure that the document has no adverse impact?

<table>
<thead>
<tr>
<th>Action</th>
<th>Lead</th>
<th>Date to be Achieved</th>
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8. Approval – At this point, you should forward the template to the Trust Equality and Diversity Lead lynbailey@nhs.net

Approved by Trust Equality and Diversity Lead: 

Date: 11.7.17
Appendix A- Advance Statement of Wishes

Planning for your future care
‘Planning for the worst and aiming for the best’

| My name: | Date of birth: |
| Address: | NHS number: |

Thinking ahead...

1. What is important to me now and in the future?

2. What would I like people who might care for me to know about my wishes / preferences.

3. What concerns I have for the future. What I worry about or fear happening.

If there is a medical treatment that you don't want to happen you may need to make an Advance Decision to Refuse Treatment
## Planning for your future care

<table>
<thead>
<tr>
<th>My name:</th>
<th>NHS number:</th>
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<table>
<thead>
<tr>
<th>My preferred place of care</th>
<th>Who will explain my wishes and preferences to health care professionals if I am unable to? (Named Spokesperson)</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home</td>
<td></td>
</tr>
<tr>
<td>Not at home</td>
<td></td>
</tr>
<tr>
<td>(Care home)</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>I have a Lasting Power of Attorney for Health</th>
<th>I have an Advance Decision to Refuse Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes □</td>
<td>Yes □</td>
</tr>
<tr>
<td>No □</td>
<td>No □</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caree's preferred place of care</th>
<th>Name:</th>
<th>It can be found:</th>
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<tbody>
<tr>
<td>At home</td>
<td></td>
<td></td>
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<tr>
<td>Not at home</td>
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<tr>
<td>(Care home)</td>
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<table>
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<th>Contact tel:</th>
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<th>Signature:</th>
<th>Date:</th>
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<tr>
<th>Date completed:</th>
<th>I have decided to review this plan on:</th>
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<tr>
<td></td>
<td>Should I lose the ability to make decisions, I give permission for this information to be shared with other relevant health &amp; social care professionals.</td>
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<tr>
<th>Family members or those identified as important to the patient involved in this Future Care Planning discussion:</th>
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<tr>
<td>Name:</td>
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<tr>
<th>Name:</th>
<th>Relationship:</th>
<th>Signature:</th>
<th>Contact tel:</th>
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<th>Name:</th>
<th>Relationship:</th>
<th>Signature:</th>
<th>Contact tel:</th>
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<tr>
<th>Healthcare Professionals involved in this Future Care Planning discussion:</th>
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<td>Name:</td>
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<th>Name:</th>
<th>Role:</th>
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If there is a medical treatment that you don’t want to happen you may need to make an Advance Decision to Refuse Treatment.
Appendix B – Advance Decision to Refuse Treatment

My Advance Decision To Refuse Treatment

<table>
<thead>
<tr>
<th>Name</th>
<th>Any distinguishing features in the event of unconsciousness</th>
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<th>Date of Birth</th>
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What this document is for?
This advance decision to refuse treatment has been written by me to specify in advance which treatments I don’t want in the future. These are my decisions about my healthcare, in the event that I have lost mental capacity and cannot consent to or refuse treatment. This advance decision replaces any previous advance decision I have made.

Advice to the reader
I have written this document to identify my advance decision. I would expect any healthcare professionals reading this document in the event I have lost capacity to check that my advance decision is valid and applicable within the meaning of the Mental Capacity Act 2005, in the circumstances that exist at the time.

Please Check
Please do not assume I have lost capacity before any actions are taken. I might need help and time to communicate.

If I have lost capacity please confirm the validity and applicability of this advance decision.

This advance decision becomes legally binding and must be followed if professionals are satisfied it is valid and applicable and meets the requirements of the Mental Capacity Act 2005. Please help to share this information with people who are involved in my treatment and care and need to know about this.

Please also check if I have made any other statements about my preferences or decisions that might be relevant to my advance decision.

This advance decision does not refuse the offer and or provision of basic care.
## My advance decision to refuse treatment

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<tr>
<th>I wish to refuse the following specific treatments:</th>
<th>In these circumstances:</th>
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(Nota to the person making this statement: If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box above that you are refusing that treatment even if your life is at risk as a result. An advance decision refusing life sustaining treatment must be signed and witnessed.)
The following list identifies which people have a copy and have been told about this Advance Decision to Refuse Treatment (and their contact details)

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<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
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Further Information (Optional)
I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my Advance Decision to refuse treatment but the reader might find it useful.

Accessing Cheshire East Council information and services
Council information is also available in Audio, Braille and Large Print formats. If you would like a copy in any of these formats or in another language, please email us at webteam@cheshireeast.gov.uk
We are also able to provide a British Sign Language (BSL) interpreter to support customers with accessing Council services.
Tel: 0300 123 5010
web: www.cheshireeast.gov.uk
Appendix C - Process and contents of an Advance Care Planning discussion
Adapted from Regnard C, Randall F 2008 (A Guide to Symptom Relief in Palliative Care, 6th ed. Oxford)

Are you the right person to do this?
No: If you are uncertain or lack knowledge of a person’s clinical condition, or their reaction to their illness, do not proceed.
Yes:

Does the person have impairment of mind?
No: Assess the person’s capacity using the four tests in the Mental Capacity Act
Yes: If the person does not have capacity for making future plans, the clinical team will need to make choices based on his/her best interests as defined in the Mental Capacity Act

Is this the person’s first discussion on future plans?
No: Ask them if they want to change their previous advance statement
Yes: Ask permission to see any documentation that is available

Does the person want to discuss their care?
No: Review the situation regularly – eg every 6 months.
Yes: Check again should the person’s circumstance change

Is the person ready to discuss end-of-life-care?
No: Many people with early or slowly progressing disease, and some with advanced disease, will not wish to discuss end-of-life care. However, they should still be given the opportunity to discuss other aspects of future care.
Yes: Ensure that the discussion and documentation do not include questions or statements about end-of-life care

Does the person want to refuse future treatment?
No: Do not use an Advance Statement of Wishes to record this decision
Yes: Discuss the option of completing an Advance Decision to Refuse Treatment (ADRT) according to the Mental Capacity Act – section 5 and Appendix 5 and 6

Ask open questions, for example:
*In relation to your health, what has been happening to you?*

*What are your preferences and priorities for your future care?*

*Where would you like to be cared for in the future?*

Allow the patient to control the flow of information.

If they do not want to discuss an aspect of their care, defer that question until another time

Check if there are any further issues:
*Are there any other issues that are important to you?*

Record the person’s preferences using the template in Appendix A

The completed document should be given to the individual - a copy of the record may be taken for the Medical and/or Nursing Records with their consent

Ask the person if, and to whom, they want copies given – eg other professionals involved in their care, family members etc

Complete the EPaCCS Template where applicable

Offer to set a review date e.g. in 6 months’ time

Does the person want the discussion documented?
No:

Yes: Document only that the discussion has taken place

Review the person’s future priorities when they request a review or when their circumstances change
Independent Mental Capacity Advocate (IMCA)  
Referral Information and Form

The IMCA Service is a statutory advocacy service introduced by the Mental Capacity Act 2005, which aims to empower and protect people who lack capacity to make decisions for themselves. For example, people with learning disabilities, dementia, mental health problems, stroke or head injuries may lack capacity to make certain decisions.

Under the Mental Capacity Act 2005 the Local Authority/ NHS body has a responsibility to instruct an IMCA when making best interest decisions for a person who lacks capacity and does not have friends or relatives appropriate to consult regarding the following decisions:

- From an NHS body in respect of decisions about providing, withholding or stopping serious medical treatment.
- From an NHS body in respect of a proposal to place the person in a hospital for a period likely to exceed 28 days or in a care home for a period likely to exceed 8 weeks.
- From an NHS body in respect of a proposal to move the person to another hospital for a period likely to exceed 28 days or to another care home for a period likely to exceed 8 weeks.
- From the Local Authority where following an assessment, it is proposed to place the person in a care home for a period likely to exceed 8 weeks or to move the person from one care home to another if the period is likely to exceed 8 weeks.

Under the Mental Capacity Act 2005 the Local Authority/NHS body may instruct an IMCA when making best interest decisions for a person who lacks capacity regarding the following:

- Care Reviews, but only where the Local Authority or NHS body have arranged the original accommodation and plan to review the arrangements (as part of a care plan or otherwise) and there are no family or friends appropriate to consult
- Adult Protection proceedings have been commenced and protective measures have already been taken or are being considered in relation to the protection of the potentially abused person or potential abuser and the Local Authority or the NHS body is satisfied that it is of particular benefit to the person for an IMCA to be appointed. Please note that there is no requirement under this provision for the person to have no appropriate family or friends.

The IMCA role is to:

- Support a person who lacks capacity
- Obtain and evaluate relevant information on behalf of the person
- Ascertain as far as possible the person's wishes and feelings
- Ascertain alternative courses of action
- Obtain a further medical opinion, where necessary
- Bring to the attention of the decision-maker all factors relevant to the decision
- Challenge the decision-maker where appropriate

**Independent Mental Capacity Advocate Referral Form**

In order to comply with data protection legislation please send completed referral forms electronically via egress to: advocacy@ageukcheshire.org.uk. If you do not have to access to egress please send them to the same email address but password protected. Please ensure the password is sent separately.

Alternatively, staff may initially make contact with the IMCA Service by telephone and on completing the referral form, can forward this by email to the Trust’s Legal Services department at ecn-tr.legalservices@nhs.net for onward transmission to the IMCA Service.

**Contact details:**

The Cheshire Advocacy Hub  
Sension House  
Denton Drive  
Northwich  
CW9 7LU

**Telephone number:** 0333 366 00 27

Upon receipt of the referral form the Cheshire Advocacy Hub will allocate this referral to an Advocate from Age UK Cheshire or Cheshire Centre for Independent Living.

This is the IMCA referral form for those seeking advocacy for anyone aged 18 and over.

<table>
<thead>
<tr>
<th>Client Name</th>
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<th>Telephone number</th>
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<tr>
<th>Current Address</th>
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<tr>
<th>Permanent Address</th>
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<tr>
<th>Age and Date of Birth</th>
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</table>
Gender
Ethnicity
Religion
GP Name & Practice

Reason for Lack of Capacity

- Learning Disability ■
- Dementia □
- Mental Health □
- Physical Disability □
- Acquired Brain Injury □
- Deaf, Blind – Deaf/Blind ■

How does the person prefer to communicate?

Decision-maker (see information sheet)

The decision maker is the individual, within the Local Authority or the NHS body who has the responsibility for making the decisions on issues of change of accommodation, serious medical treatment, care review or adult protection on behalf of the client who has been assessed as lacking capacity on any stated issue.*

Name & Designation
Address & Telephone

Referrer (insert details only if different to decision maker)

Name
Contact
Address/Telephone
*Issue (see information sheet)*

- Serious Medical Treatment
- Change in Accommodation by NHS/LA
- Care Review
- Adult Protection

All the following questions **must** be answered:-

I confirm that for the above issue I am the decision-maker on behalf of *(insert NHS body or Local Authority)*

I confirm that I deem the client to be unbefriended, with no-one appropriate to consult regarding this issue.

I also confirm that the client has been deemed to lack capacity to make a decision regarding the above issue and that the required (decision specific) capacity assessment has been carried out by *(insert name and position of assessor)*

**Please describe the decision that is to be made**


**Is there any information the advocate needs in order to keep the person and/or the advocate safe (e.g. health or behavioural issues?)**


**I confirm that I am the decision-maker for**


Signature ........................................... Date ............................................

**Please print name** .................................................................