

The Marie Curie
Palliative Care Institute

LIVERPOOL

LCP CENTRAL TEAM

**Liverpool Care Pathway for the Dying Patient (LCP)
Supporting care in the last hours or days of life**

Goal Definitions - Data Dictionary for LCP ICU version 12

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MAY 2011

**GUIDANCE REGARDING GOALS
LCP ICU VERSION 12**

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BACKGROUND

What is the Liverpool Care Pathway for the Dying Patient (LCP)

Over the past few years a major drive has been underway to ensure that all dying patients, and their relatives and carers receive a high standard of care in the last hours or days of their life. The Liverpool Care Pathway for the Dying Patient (LCP) within the LCP continuous quality improvement programme is one of the key programmes within the Marie Curie Palliative Care Institute Liverpool (MCPCIL) portfolio.

The aim of the LCP is to improve care of the dying in the last hours or days of life by improving knowledge related to the process of dying and the quality of care. It comprises 3 key sections (Initial Assessment, Ongoing Assessment and Care after Death) and covers 4 domains of care (Physical, Psychological, Social and Spiritual). The continuous quality improvement programme involves transferring the excellent model hospice care for the dying into other health care settings and to develop outcome measures using an integrated care pathway (ICP) for the last hours or days of life. A care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well defined group of patients during a well defined period. Dr Kris Vanaecht, Secretary General of the European Pathway Association suggests that the defining characteristics of care pathways include the following 5 Key elements :

1. An explicit statement of goals / key elements of care based on evidence, best practice
2. The facilitation of the communication among team members & with patient's & families
3. The coordination of the care process by coordinating the roles & sequencing the activities of the MDT, patients & carers
4. The documentation, monitoring & evaluation of variances & outcomes
5. The identification of the appropriate resources

Successful implementation ensures that the LCP is embedded within the organisational governance of individual organisations. It requires local clinical decision making and management and leadership and is underpinned by learning and teaching and research and development. Recognition of the fundamental aspects of change management is pivotal to empower, enable and engage colleagues and the MCPCIL has developed a 10 Step Continuous Quality Improvement Programme within a 4 phased approach to support the implementation of the LCP into a range of environments. (Ellershaw & Wilkinson, 2011; www.mcpcil.org.uk)

The LCP was recognised in England as a model of best practice in the NHS Beacon Programme (2001). It was then subsequently incorporated into the Cancer Services Collaborative project and the National End of Life Care Programme (2004-7). It was recommended in the NICE guidance on supportive and palliative care for patients with cancer (2004) as a mechanism for identifying and addressing the needs of dying patients. It was recommended in the Our Health, Our Care, Our Say white paper 2006 as a tool that should be rolled out across the country. It is recommended in the End of Life Care Strategy DH (2008) and highlighted in the Department of Health End of Life Care Quality Markers document (2009). In December 2009 after an extensive, 2 year national and international consultation process, Version 12 of the LCP was launched.

Implementation of LCP ICU Version 12 across Intensive Care Units within Merseyside and Cheshire Cancer Network (MCCN) – Project Background

The LCP ICU project is co-ordinated by the Marie Curie Palliative Care Institute Liverpool (MCPCIL), sponsored and funded by the Merseyside and Cheshire Cancer Network (MCCN) on behalf of the Cheshire and Mersey Critical Care Network (CMCCN).

A number of years ago, the LCP was adopted and implemented in the Intensive Care Unit (ICU) in the Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT) within an action research project of continuous quality improvement. Subsequently, a national LCP ICU study day was held as a joint project with Marie Curie Palliative Care Institute Liverpool (MCPCIL) and the palliative care section of the Royal Society of Medicine to disseminate the learning from this project and to encourage other units to consider implementation of the LCP ICU. To date more than 90 Intensive Care Services across the UK are registered to use LCP ICU Version 11 and some units within CMCCN successfully implemented the LCP ICU Version 11 or equivalent as part of this process.

Since the launch of the LCP generic version 12 in December 2009, the local pilot ICU Action Research group at RLBUHT, working with the LCP Central Team, LCP ICU Facilitator and other ICU colleagues have created the LCP ICU Version 12. The proposed project to implement LCP ICU Version 12 in all intensive care services within the CMCCN will be a key step towards greater consistency across the health economy. It will provide a template for innovative change management for care in the last hours or days of life within the CMCCN and eventually lead to wider national and international dissemination of the LCP ICU Version 12.

NB The LCP ICU Version 12 document and this Goal Data Dictionary, may require further amendment in light of the findings from this pilot project.

Key Messages for the healthcare professional using the LCP ICU version 12

The LCP ICU is only as good as the teams using it and must be underpinned by a robust ongoing education and training programme. As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement.

10 KEY LCP ICU Messages

1. **The LCP ICU is only as good as the people who are using it**
2. **The LCP ICU should not be used without the support of education & training**
3. **Good communication is pivotal to success**
4. **The LCP ICU neither hastens nor postpones death**
5. **Diagnosis of dying should be made by the multidisciplinary team (MDT)**
6. **The LCP ICU does not recommend the use of continuous deep sedation**
7. **The LCP ICU does not preclude the use of artificial hydration**
8. **The LCP ICU supports continual reassessment**
9. **Reflect, Audit, Measure & Learn**
10. **Stop, Think, Assess & Change**

The responsibility for the use of the LCP ICU version 12 document as part of a continuous quality improvement programme sits within the governance of an organisation and must be underpinned by a robust education and training programme

USING THE LCP ICU

This LCP ICU Goal Data Dictionary has been developed to enable a more explicit and robust understanding of the core meaning of each of the goals of care and the rationale, required behaviour and correct coding of information. Some key terms and relevant processes are also explained to facilitate understanding and underpin the correct use of the LCP ICU.

What is meant by the term “Variance”?

Variance (exception reporting) on an integrated care pathway is a mechanism by which a seemingly process driven approach to care can be tempered in line with individual patient need. The potential to use clinical skill and judgement to deviate from the suggested plan of care in response to individual patients makes the LCP a more flexible and practical document.

Variance provides other clinicians in the environment with a clear picture regarding the choices made and the care delivered. Focusing specifically on the variance sheets allows clinicians to see at a glance what the major issues have been for the patient (and relative or carer) over a given period of time.

When variance recording is studied over a cross section of patients, it can also highlight organisational or educational issues that may be impacting on the delivery of care in a given environment. Taking care to document carefully on the variance sheet can, therefore, provide a wealth of important information for clinicians and managers alike.

Failing to document variance appropriately tells us nothing!

Variance recording tells the true story of the patient’s journey / condition. If the variance is not completed then we do not have documented evidence of the care that was delivered, nor care that requires action.

The LCP ICU version 12 document

Healthcare professional information – LCP ICU version 12

As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement

- ❑ This document has been designed to support patients who require ICU Level 3 care. Intensive Care Society (ICS) Definition of ICU level 3 care – Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least 2 organ systems. All complex patients requiring support for Multiple Organ Failure. *Intensive Care Society 2009.*
- ❑ The LCP ICU may be used to support patients who require Level 2 care if they are cared for in an environment where the management of the patient is coordinated by the ICU Team.
- ❑ The LCP ICU document guides and enables healthcare professionals to focus on care in the last hours or days of life of the level 3 ICU patient. This provides high quality care tailored to the patient's individual needs, when their death is expected.
- ❑ Using the LCP ICU requires regular assessment and involves continuous reflection, challenge, critical senior decision-making and clinical skill, in the best interest of the patient. A robust continuous learning and teaching programme must underpin the use of the LCP ICU.
- ❑ The recognition and diagnosis of dying is always complex; irrespective of previous diagnosis or history. Uncertainty is an integral part of dying. There are occasions when a patient who is thought to be dying lives longer than expected and vice versa. Seek a second opinion or specialist palliative care support as needed.
- ❑ Changes in care at this complex, uncertain time are made in the best interest of the patient and relative or carer and needs to be reviewed regularly by the ICU Multi-disciplinary Team (MDT).
- ❑ Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate and to the relative or carer. The views of all concerned must be listened to and documented.
- ❑ If a goal on the LCP ICU is not achieved this should be coded as a variance. This is not a negative process but demonstrates the individual nature of the patient's journey based on their particular needs, your clinical judgement and the needs of the relative or carer.
- ❑ The LCP ICU does not preclude the use of clinically assisted nutrition, hydration or antibiotics. All clinical decisions must be made in the patient's best interest. A blanket policy of clinically assisted (artificial) nutrition or hydration, or of no clinically assisted (artificial) hydration, is ethically indefensible and in the case of patients lacking capacity prohibited under the Mental Capacity Act (2005).

The patient will be assessed regularly and a formal full ICU MDT review must be undertaken every 24 hours

For the purpose of this LCP ICU version 12 document - The term best interest includes medical, physical, emotional, social and spiritual and all other factors relevant to the patient's welfare.

The responsibility for the use of the LCP ICU document as part of a Continuous Quality Improvement Programme sits within the governance of an organisation and must be underpinned by a robust education and training programme.

Multidisciplinary Team (MDT) Decision Making

The individual organisation will need to determine the personnel who constitute a multidisciplinary team (MDT). As a minimum the MDT is usually a doctor and a nurse but may include other healthcare professionals / other personnel as appropriate.

The recognition and diagnosis of dying is always complex; irrespective of previous diagnosis or history. The LCP ICU version 12 includes a helpful algorithm to support the clinical decision making process regarding the recognition and diagnosis of dying and use of the LCP ICU to support care in the last hours or days of life.

The MDT assessment will include the following:

- Is there a potentially reversible cause for the patient's condition e.g. exclude Opioid toxicity, renal failure, hypercalcaemia, infection
- Could the patient be in the last hours or days of life?
- Is Specialist referral needed? e.g. specialist palliative care or a second opinion

If the patient is diagnosed as dying (in the last hours or days of life) then this should be communicated appropriately. Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate and to the relative or carer. The views of all concerned must be listened to and documented. All decisions must be documented accordingly on the LCP ICU.

This process should reflect other elements of healthcare clinical decision making.

For example: when a decision is made to record a do not attempt cardiopulmonary resuscitation order, this decision must be made by the most senior healthcare professional immediately available in the environment, documented and witnessed according to local policy and procedure within the organisational governance framework. This decision is then endorsed by the most senior healthcare professional responsible for the patient's care at the earliest opportunity.

LCP ICU version 12 calls for the same decision making process to be followed when diagnosing dying and commencing the LCP.

Healthcare professional documenting the ICU MDT decision

Following a full ICU MDT assessment and a decision to use the LCP ICU:

Date LCP ICU commenced:.....

Time LCP ICU commenced:.....

Consultant's Name (ICU):.....

Discussion with referring team if applicable Yes No N/A

Name:.....

ICU Consultant's Signature:.....

SECTION 1

INITIAL ASSESSMENT

GOALS 1.1 - 1.2 - 1.3 - 1.4 - 1.5 - COMMUNICATION

GOAL 1.1	The patient is able to take a full and active part in communication
Rationale	<p>Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate. The views of all concerned must be listened to and documented and the aim is for all patients, unless unconscious, to be able to take a full and active part in communication:</p> <ul style="list-style-type: none"> ○ To support communication / psychological well-being / insight into care management and to assess for barriers that have the potential to prevent clear communication ○ For example, some patients may not use English as their first language or have physical or learning disabilities and may need additional support to enable full engagement in communication.
Required Behaviour	<p>Assess the communication status of the patient and:</p> <ul style="list-style-type: none"> ● If English is not the patient’s first language, consider the need for interpreting service and make it available to the patient as required ● If the patient has physical or learning disabilities (e.g. Hearing, vision, speech, learning disabilities, dementia (use of assessment tools), neurological conditions, confusion etc. Consider the need for additional support and make it available to the patient as required ● Document all discussions accordingly and in full between ICU MDT, patient, relatives or carers on the ICU MDT discussion sheet.
Coding	<p>Code Achieved either</p> <ul style="list-style-type: none"> ● when no support is needed to facilitate appropriate communication with the patient ● when the support required is available at this moment in time <p>Code Variance when</p> <ul style="list-style-type: none"> ● you have identified the need for support to facilitate appropriate communication with patient but it is not available at this moment in time <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p> <p>Code Unconscious if the patient is unconscious and is therefore not able at this moment in time to take a full and active part in communication.</p> <p><i>This does not mean you will stop speaking with your patient and continue to explain the plan of care, but you cannot be sure the patient fully understands.</i></p>

GOAL 1.2	The relative or carer is able to take a full and active part in communication
Rationale	<p>Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the relative or carer where appropriate. The views of all concerned must be listened to and documented to enable relatives or carers to take a full and active part in communication:</p> <ul style="list-style-type: none"> ○ To support communication / psychological well-being / insight into care management of the patient, and to assess for barriers that have the potential to prevent clear communication ○ For example, some relatives or carers may not use English as their first language or have physical or learning disabilities and may need additional support to enable full engagement in communication.
Required Behaviour	<p>Assess the communication status of the relative or carer(s) and:</p> <ul style="list-style-type: none"> ● If English is not their first language, consider the need for an interpreting service and make it available to them as required ● If the relative or carer(s) have physical or learning disabilities (e.g. Hearing, vision, speech, learning disabilities, dementia (use of assessment tools), neurological conditions, confusion etc. Consider the need for additional support and make it available to them as required
Coding	<p>Code Achieved either</p> <ul style="list-style-type: none"> ● when no support is needed to facilitate appropriate communication with the relative or carer(s) ● when the support required is available at this moment in time
	<p>Code Variance when</p> <ul style="list-style-type: none"> ● you have identified the need for support to facilitate appropriate communication with relative or carer(s), but it is not available at this moment in time <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 1.3	The patient is aware that they are dying
Rationale	<p>Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate. The views of all concerned must be listened to and documented.</p> <ul style="list-style-type: none"> ○ To ensure that the patient is aware that they are now thought to be dying and in the last hours or days of life ○ To ensure that you as a healthcare professional are aware of the knowledge status of the patient to support future conversations you may have (particularly at the bedside) in order to maintain appropriate confidentiality and respect
Required Behaviour	<ul style="list-style-type: none"> ● You should have a conversation with the patient at this moment in time to assess their level of awareness and to explain to them that death is expected in the coming hours or days. It is important that you check the understanding of the patient after you have communicated with them. ● There may be a very valid reason for not undertaking a conversation with the patient at this time, for example: <ul style="list-style-type: none"> ➢ patient requested not to be told bad news ➢ patient is alone & you want to have this conversation with a relative or carer present ➢ patient is not well enough in your healthcare professional opinion to have this discussion despite being conscious ➢ you do not feel able to address this issue at this time ● If a conversation is deemed appropriate at this time, remember, it can be a difficult conversation to have. You need to recognise your limitations and seek advice and support where appropriate ● Document all discussions accordingly and in full between ICU MDT, patient, relatives or carers on the ICU MDT discussion sheet.
Coding	<p>Code Achieved if you have had a conversation with the patient at this moment in time, you have explained that they are deemed to be dying and in the last hours and days of life and you are confident that the patient is fully aware.</p> <hr/> <p>Code Variance</p> <ul style="list-style-type: none"> ● If you have had a conversation regarding these issues with the patient at this time, but you are not confident that the patient is fully aware. ● You did not have a conversation regarding these issues with the patient at this time ● <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p> <hr/> <p>Code Unconscious if you have not had a conversation with the patient to explain that they are in the last hours or days of life at this time because the patient is unconscious.</p> <p><i>This does not mean you will stop speaking with your patient and continue to explain the plan of care, but you cannot be sure the patient fully understands.</i></p>

GOAL 1.4	The relative or carer is aware that the patient is dying
Rationale	<p>Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate. The views of all concerned must be listened to and documented.</p> <ul style="list-style-type: none"> ○ To ensure that the relative or carer is aware that the patient is now thought to be dying and in the last hours or days of life ○ To ensure that you as a healthcare professional are aware of the knowledge status of the relative or carer to support future conversations you may have (particularly at the bedside) in order to maintain appropriate confidentiality and respect
Required Behaviour	<ul style="list-style-type: none"> ● You should have a conversation with the relative or carer at this moment in time to assess their level of awareness and to explain to them that the patient is expected to die in the coming hours or days. It is important that you check the understanding of the relative or carer after you have communicated with them. ● There may be a very valid reason for not undertaking a conversation with the relative or carer at this time, for example: <ul style="list-style-type: none"> ○ The relative or carer although available may be physically or psychologically frail, or elderly themselves and due to your risk assessment of the situation you want to wait to discuss these issues when extended support is available ○ you do not feel able to address this issue at this time ● If a conversation is deemed appropriate at this time, remember, it can be a difficult conversation to have. You need to recognise your limitations and seek advice and support where appropriate ● Document all discussions accordingly and in full between ICU MDT, patient, relatives or carers on the ICU MDT discussion sheet.
Coding	<p>Code Achieved if you have had a conversation with the relative or carer at this moment in time, you have explained that the patient is deemed to be dying and in the last hours and days of life and you are confident that the relative or carer is fully aware.</p> <p>Code Variance</p> <ul style="list-style-type: none"> ● If you have had a conversation regarding these issues with the relative or carer at this time, but you are not confident that they are fully aware. ● You did not have a conversation regarding these issues with the relative or carer at this time <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 1.5	The opportunity for organ/tissue donation is considered by the ICU MDT and the Specialist Nurse in organ donation has been contacted
Rationale	<ul style="list-style-type: none"> ○ To ensure that any expressed wish by the patient and or their relatives or carers are highlighted and addressed and that any specific needs or wishes are documented on the LCP ICU. ○ To ensure the correct personnel are available to discuss needs and wishes with the patient and their relatives and carers are documented on the LCP ICU in a timely manner
Required Behaviour	<ul style="list-style-type: none"> ● A conversation must take place between the ICU MDT and the specialist nurse in organ donation and documented in full on the Initial assessment ICU MDT progress notes (page 9 - LCP ICU Version 12)
Coding	<p>Code Achieved</p> <ul style="list-style-type: none"> ● If the MDT has considered the opportunity for organ/tissue donation and the specialist nurse in organ donation has been contacted
	<p>Code Variance</p> <ul style="list-style-type: none"> ● if the MDT has not considered the opportunity for organ donation ● if the MDT has considered the opportunity for organ donation but the specialist nurse for organ donation had NOT been contacted <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 1.6	The clinical team have up to date contact information for the relative or carer as documented below
Rationale	<ul style="list-style-type: none"> ○ It is important when communicating information of a sensitive nature around the patient's deteriorating condition / impending death that the appropriate person can be contacted at an appropriate time ○ Information that was accurate at any other time in this episode of care may not be accurate now that the patient is thought to be in the last hours or days of life ○ Some carers may be working, elderly or indeed not want to be contacted until the following day irrespective of the patient's condition ○ Establishing how a relative or carer wish to be told of a patient's impending death is also very important ○ In some situations the next of kin may not be the most appropriate person to be contacted at the time of impending death or a list of people may be given or mobile numbers may be needed
Required Behaviour	<ul style="list-style-type: none"> ● Irrespective of prior knowledge or documentation the healthcare professional must revisit this issue and have a conversation to ensure that contact details have been revisited to ensure the correct details are documented correctly
Coding	<p>Code Achieved if you have had a conversation with the relative or carer and you have identified and documented;</p> <ul style="list-style-type: none"> ▪ The first & second contact names ▪ Appropriate times & circumstances when this person(s) should be contacted ▪ The contact information for the Next of Kin (NOK)/ Lasting Power of Attorney (LPA) <p>Code Variance if you have NOT had this conversation and, as a result, updated accurate information cannot be guaranteed.</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 2 - FACILITIES

GOAL 2:	The relative or carer has had a full explanation of the facilities available to them, and an ICU facilities leaflet has been given
Rationale	<ul style="list-style-type: none"> ○ It is important that relatives or carers are fully informed verbally by the healthcare professional and have supportive written information to outline the facilities available to them at this time. Remember information received verbally only may not be retained at this sad and challenging time. ○ In an ICU this could include - car parking, public transport, refreshments, cash machine, pay phone, accommodation, chaplaincy support, access to a nurse call bell
Required Behaviour	<ul style="list-style-type: none"> ● A conversation must take place and written information be given to the relative or carer to support this conversation
Coding	Code Achieved if you have had a conversation with the relative or carer at this moment in time and given a written information leaflet to support this conversation. BOTH of these elements need to be undertaken if this goal is to be achieved.
	<p>Code Variance if:</p> <ul style="list-style-type: none"> ● You have not had a conversation at this moment in time (even if you have given an information leaflet) ● You have had a conversation at this moment in time, but NOT given an information leaflet ● You have not had a conversation or given an information leaflet at this moment in time <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOALS 3.1 - 3.2 - SPIRITUALITY

GOAL 3.1	The patient is given the opportunity to discuss what is important to them at this time e.g. their wishes, feelings, faith, beliefs, values, organ donation
Rationale	<ul style="list-style-type: none"> ○ To ensure that any spiritual need is highlighted and addressed if required now, at death or after death and any specific needs are documented on the LCP ICU to aid and inform other healthcare professionals/other personnel who may become involved in the patient's care
Required Behaviour	<ul style="list-style-type: none"> • Even if it is known that the patient has previously been asked about their spiritual beliefs and may indeed have a documented formal religious tradition or spiritual belief on admission, a conversation to identify the patient's present spiritual / religious / cultural needs must be undertaken • The needs must be documented appropriately on the LCP ICU. • NB If the patient is unable to have this conversation with you, you may wish to discuss the patient's needs or wishes with the relative or carer.
Coding	Code Achieved if you had a conversation with the patient at this moment in time and any religious / spiritual / cultural needs (or their absence) have been identified and documented appropriately.
	Code Variance if you have not had a conversation regarding these issues with the patient (for example, because they were confused, too drowsy etc) A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.
	Code Unconscious if it was impossible to have the conversation because your patient is unconscious at this moment in time. <i>This does not mean you will stop speaking with your patient and continue to explain the plan of care, but you cannot be sure the patient fully understands.</i>

GOAL 3.2	The relative or carer is given the opportunity to discuss what is important to them at this time e.g. their wishes, feelings, faith, beliefs, values
Rationale	<ul style="list-style-type: none"> ○ To ensure that any spiritual need is highlighted and addressed if required now, at death or after death of the patient and any specific needs are documented on the LCP to aid and inform any other healthcare professionals / other personnel who may be involved in the patient's care.
Required Behaviour	<ul style="list-style-type: none"> • Irrespective of any prior discussions, it is important to have a direct conversation at this time to identify the spiritual/religious or cultural needs of the relative or carer and offer appropriate support, now, at the patient's death or after death. The outcome of this conversation must be documented on the LCP ICU. <p>NB Where the patient has been unable to have a similar conversation with you (goal 3.1), you may wish to discuss the patient's needs or wishes with the relative or carer</p>
Coding	Code Achieved if you had a conversation with the relative or carer at this moment in time and any religious / spiritual / cultural needs (or their absence) have been identified and documented appropriately.
	Code Variance if you have NOT had this conversation at this time
	A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.

GOALS 4.1 - 4.2 - MEDICATION

GOAL 4.1	The patient has medication prescribed on a prn basis for all of the following 5 symptoms which may develop in the last hours or days of life
Rationale	<ul style="list-style-type: none"> ○ These 5 main symptoms have been recognised as actual or potential problems in the last hours or days of life ○ Anticipatory prescribing will ensure minimal delay in responding to a symptom if or when it arises. Medicines for symptom control should only be given when needed, at the right time and just enough and no more than is needed to help control the symptom and titrated according to individual patient need.
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement and all decisions must be made in the patient's best interest</p> <p>Anticipatory prescribing will ensure minimal delay in responding to a symptom if or when it arises. Medicines for symptom control should only be given when needed, at the right time and just enough and no more than is needed to help control the symptom and titrated according to individual patient need.</p> <ul style="list-style-type: none"> • Refer to the algorithms at the end of the LCP ICU (developed according to your local policy and procedure) to underpin prescribing (appropriate medications/dose etc) • Prescribe appropriate PRN medication for all 5 main symptoms (whether or not the patient is displaying these symptoms on commencement of the LCP ICU) • Assess all current medication and discontinue any non essential medication
Coding	<p>Code Achieved when all of the appropriate medications have been written up according to protocol for all 5 main symptoms that may occur in the last hours or days of life</p> <hr/> <p>Code Variance when appropriate medications have NOT been written up according to protocol for all 5 main symptoms that may occur in the last hours or days of life</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU</p>

GOAL 4.2	The patient has equipment to support a continuous infusion of medication where required
Rationale	<ul style="list-style-type: none"> ○ To ensure that equipment supporting continuous IV / CSCI infusion of medication in support of symptom management is available where required. ○ If a patient is to be transferred to ward, home or hospice ensure equipment to support IV / CSCI is in place.
Required Behaviour	<ul style="list-style-type: none"> ● Stop, Think, Assess, and Change your practice accordingly. ● If medication is required to be given via a IV / CSCI then obtain the appropriate equipment required & use according to local policy and procedure
Coding	Code Achieved if equipment is needed and available at this moment in time to support IV / CSCI of medication.
	Code Variance when equipment is needed but NOT available at this moment in time to support IV / CSCI of medication.
	A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.
	Code Already in place if equipment for IV / CSCI is already in progress at the time the LCP ICU is commenced.
	Code Not Required if equipment is not needed to support IV / CSCI medication at this moment in time.

GOALS 5.1 - 5.2 - 5.3 - CURRENT INTERVENTIONS

GOAL 5.1	The patient's need for current interventions has been reviewed by the MDT
Rationale	<p>The LCP ICU version 12 document guides and enables healthcare professionals to focus on care in the last hours or days of life. This provides high quality care tailored to the patient's individual needs, when their death is expected:</p> <ul style="list-style-type: none"> ○ To avoid invasive, futile, potentially painful and unnecessary procedures / interventions being carried out when no clear benefit can be gained. All decisions taken regarding interventions (ie to be continued, discontinued or commenced) must be considered to be in the patient's best interest at this moment in time.
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement. Stop, Think, Assess, and Change your practice accordingly</p> <ul style="list-style-type: none"> ● Assess the patient's status regarding the following interventions: <ul style="list-style-type: none"> ➤ 5a Routine blood tests ➤ 5b Intravenous antibiotics ➤ 5c Blood glucose monitoring ➤ 5d Recording of routine vital signs ➤ 5e Oxygen therapy ➤ 5f Physiotherapy ➤ 5g I.V Vasoactive Medications ➤ 5h Electronic Monitoring ➤ 5i Renal Replacement Therapy ➤ 5j NG tube (Gastric secretions) ➤ 5k Current Ventilatory Support being received ● Continue, discontinue or commence as appropriate in the patient's best interest at this moment in time
Coding	<p>Code Achieved when each of the specific interventions above (5a, 5b, 5c, 5d, 5e) have been assessed and an outcome is clearly recorded on the LCP.</p> <p>Code Variance if any of the specific interventions above (5a, 5b, 5c, 5d, 5e, 5f, 5g, 5h, 5i, 5j, 5k) have NOT been assessed and/or an outcome is NOT recorded on the LCP ICU.</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 5.2	The patient has a Do Not Attempt Cardiopulmonary Resuscitation Order in place
Rationale	<p>The LCP ICU version 12 document guides and enables healthcare professionals to focus on care in the last hours or days of life. This provides high quality care tailored to the patient's individual needs, when their death is expected.</p> <ul style="list-style-type: none"> ○ To avoid invasive, futile, potentially painful and unnecessary cardio pulmonary resuscitations procedures / interventions being carried out when no clear benefit can be gained. All interventions must be considered to be in the patient's best interest.
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement and all decisions must be made in the patient's best interest. Stop, Think, Assess, and Change your practice accordingly</p> <ul style="list-style-type: none"> ● Assess the cardiopulmonary resuscitation status of the patient
Coding	<p>Code Achieved when a 'not for DNA CPR' decision has been made and appropriately documented according to policy/procedure.</p> <p>Code Variance</p> <ul style="list-style-type: none"> ● when there is no clear decision in place at this moment in time ● when a decision has been made to attempt CPR when deemed appropriate ● where no documentation exists regarding the patient's CPR status at this moment in time <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 5.3	Implantable Cardioverter Defibrillator (ICD) is deactivated
Rationale	<ul style="list-style-type: none"> ○ Continuing cardiac defibrillation until the point of death can be distressing and confusing to relative or carers when no clear benefit can be gained. All interventions must be considered to be in the patient's best interest.
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement. Stop, Think, Assess, and Change your practice accordingly</p> <ul style="list-style-type: none"> ● Refer to and follow local policy and procedures for deactivation ● Contact the patient's cardiologist ● Give information leaflet to patient / relative or carer wherever appropriate in support of best practice
Coding	Code Achieved when the ICD has been deactivated at this moment in time according to policy and procedure.
	Code Variance where <ul style="list-style-type: none"> ● an ICD is in place but has not been deactivated ● a plan has been agreed for deactivation but has not occurred at this moment in time <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>
	Code no ICD in place where the patient does not have an ICD in place

GOAL 6 – NUTRITION

GOAL 6:	The need for clinically assisted (artificial) nutrition is reviewed by the ICU MDT
Rationale	<ul style="list-style-type: none"> ○ The LCP ICU does not preclude the use of clinically assisted (artificial) nutrition. All clinical decisions must be made in the patient’s best interest. ○ A blanket policy for giving assisted (artificial) nutrition or for not giving clinically assisted (artificial) nutrition is ethically indefensible and in the case of patients lacking capacity prohibited under the Mental Capacity Act (2005). ○ A full assessment of the patient’s need for this intervention is required and communication with the patient, where possible, and relative or carer is essential at this moment in time. ○ For many patients the use of clinically assisted (artificial) nutrition will not be required but again this decision must be made in the patient’s best interest. ○ A reduced need for food is part of the normal dying process.
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement and all decisions must be made in the patient’s best interest. The MDT must Stop, Think, Assess, and Change practice accordingly</p> <ul style="list-style-type: none"> ● The patient should be supported to take food by mouth for as long as tolerated. ● An assessment of the patient’s need for clinically assisted (artificial) nutrition should be undertaken ● The outcome of decisions made must be documented on the LCP ICU
Coding	<p>Code Achieved when the MDT has reviewed the need for the use of clinically assisted (artificial) nutrition, the outcome is clearly communicated with the patient (where possible) and with the relative or carer, and documented on the LCP ICU at this moment in time.</p> <hr/> <p>Code Variance when the MDT has NOT reviewed the need for the use of clinically assisted (artificial) nutrition AND/OR not discussed with the relative or carer</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 7 – HYDRATION

GOAL 7:	The need for clinically assisted (artificial) hydration is reviewed by the ICU MDT
Rationale	<ul style="list-style-type: none"> ○ The LCP ICU does not preclude the use of clinically assisted (artificial) hydration. All clinical decisions must be made in the patient’s best interest. ○ A blanket policy for giving clinically assisted (artificial) hydration or for not giving clinically assisted (artificial) hydration, is ethically indefensible and in the case of patients lacking capacity prohibited under the Mental Capacity Act (2005). ○ A full assessment of the patient’s need for this intervention is required and communication with the patient, where possible, and relative or carer is essential at this moment in time. ○ For many patients the use of clinically assisted (artificial) hydration will not be required but again this decision must be made in the patient’s best interest. ○ A reduced need for fluids is part of the normal dying process.
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement and all decisions must be made in the patient’s best interest. The MDT must Stop, Think, Assess, and Change practice accordingly</p> <ul style="list-style-type: none"> ● The patient should be supported to take fluids by mouth for as long as tolerated. ● The outcome of decisions made must be documented on the LCP ICU.
Coding	<p>Code Achieved when the MDT has reviewed the need for the use of clinically assisted (artificial) hydration, the outcome is clearly communicated with the patient (where possible) and with the relative or carer, and documented on the LCP ICU at this moment in time.</p> <hr/> <p>Code Variance when the MDT has NOT reviewed the need for the use of clinically assisted (artificial) hydration AND/OR not discussed with the relative or carer</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU</p>

GOAL 8 - SKIN CARE

GOAL 8:	The patient's skin integrity is assessed
Rationale	<ul style="list-style-type: none"> ○ The aim is to prevent pressure ulcers or further deterioration if a pressure ulcer is present. ○ To develop a plan of care regarding skin integrity / skin care for this moment in time and ensure that the clinical team are fully aware of the plan
Required Behaviour	<p>As with all clinical guidelines and pathways the LCP ICU aims to support but does not replace clinical judgement and all decisions must be made in the patient's best interest. Stop, Think, Assess, and Change your practice accordingly.</p> <ul style="list-style-type: none"> ● Use a recognised risk assessment tool e.g. Waterlow / Braden to support clinical judgement. ● Determine the frequency of repositioning through the inspection of the patient's skin, according to the patient's individual needs ● Consider the use of special aids (mattress / bed) ● Record the plan of care on the initial assessment MDT sheet
Coding	Code Achieved when skin integrity has been fully assessed & plan documented on the LCP ICU at this moment in time.
	Code Variance when an assessment of skin integrity and associated plan is NOT undertaken AND/OR documented at this moment in time. A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.

GOAL 9.1- 9.2 - 9.3 - 9.4

EXPLANATION OF THE PLAN OF CARE

GOAL 9.1	Full explanation of the current plan of care (LCP ICU) is given to the patient
Rationale	<ul style="list-style-type: none"> ○ It is important to ensure that the patient fully understands the aims of the current plan of care (LCP ICU) and that the focus is now on ensuring comfort during the last hours or days of life and is supported by best practice. ○ It is important not to assume understanding but to check what the patient has understood.
Required Behaviour	<ul style="list-style-type: none"> • Irrespective of any prior discussions undertake a direct conversation at this time to ensure the patient understands how care will be delivered • Seek appropriate support for any barriers to communication
Coding	<p>Code Achieved when you have had a conversation and you are confident that the patient fully understands the current plan of care (LCP ICU).</p> <p>Code Variance when</p> <ul style="list-style-type: none"> • you have NOT had a conversation • you have had a conversation but you are not confident that the patient fully understands the current plan of care <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p> <p>Code Unconscious if it is impossible to have the conversation because the patient is unconscious at this moment in time.</p> <p><i>This does not mean you will stop speaking with your patient and continue to explain the plan of care, but you cannot be sure the patient fully understands.</i></p>

GOAL 9.2	Full explanation of the current plan of care (LCP ICU) is given to the relative or carer
Rationale	<ul style="list-style-type: none"> ○ It is important to ensure that the relative or carer fully understands the aims of the current plan of care (LCP ICU) and that the focus is now on ensuring comfort during the last hours or days of life and is supported by best practice. ○ It is important not to assume understanding but to check what the relative or carer has understood.
Required Behaviour	<ul style="list-style-type: none"> ● Irrespective of any prior discussions undertake a direct conversation at this time to ensure the relative or carer understands how care will be delivered. ● List the healthcare professionals & relatives or carers who were present when this conversation took place ● Seek appropriate support for any barriers to communication. ● Access to age appropriate advice and information to support children/adolescents at this time should be made available.
Coding	Code Achieved when you have had a conversation AND you are confident the relative or carer fully understands the plan of care AND the information sheet at the front of the LCP has been given to the relative or carer to support this conversation.
	Code Variance when <ul style="list-style-type: none"> ● you have NOT had a conversation ● you have had a conversation but you are not confident that the relative or carer fully understands the current plan of care ● No information leaflet given <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 9.3	The LCP Coping with dying leaflet or equivalent is given to the relative or carer
Rationale	<ul style="list-style-type: none"> ○ This leaflet supports a conversation that has taken place with the relative or carer to explain the changes which may occur over the coming hours or days so that the relative or carer understands these changes and feels supported.
Required Behaviour	<ul style="list-style-type: none"> ● Give the LCP coping with dying leaflet or equivalent to the relative or carer and offer support at this moment in time. ● Indicate that if further questions, fears or concerns do arise a member of the team will be pleased to listen and offer support or explanation & answer any questions.
Coding	Code Achieved when you have given the LCP coping with dying leaflet or equivalent to the relative or carer.
	Code Variance when you have NOT given the LCP coping with dying leaflet or equivalent to the relative or carer. A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.

GOAL 9.4	The patient's primary health care team / GP Practice is notified that the patient is dying
Rationale	<ul style="list-style-type: none"> ○ The primary health care team should always be kept informed of the patient's condition as the patient is always registered under their care. ○ They need to know that the focus of care has changed and an LCP ICU is in progress because other members of the family may be known to the practice and may seek support. ○ The GP or other member of the primary healthcare team may want to visit the patient or carer.
Required Behaviour	<ul style="list-style-type: none"> ● Contact the primary health care team and ensure all appropriate personnel are notified of the current diagnosis of dying and plan of care (LCP ICU). ● In the ICU it would be appropriate to contact the GP practice - have a conversation where possible or leave a message or secure fax out of hours to inform the practice of the current change in the plan of care.
Coding	<p>Code Achieved when you have notified the primary healthcare team / GP practice.</p> <p>Code Variance when you have NOT notified the primary healthcare team / GP practice</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

SECTION 2

ONGOING ASSESSMENT

In the ongoing assessment section it is the condition of the patient that is assessed (i.e. whether the patient is comfortable against a series of specific goals of care).

The frequency of any assessments or review of a patient in the last hours or days of life depend on the individual needs of the patient and /or relative or carer.

However

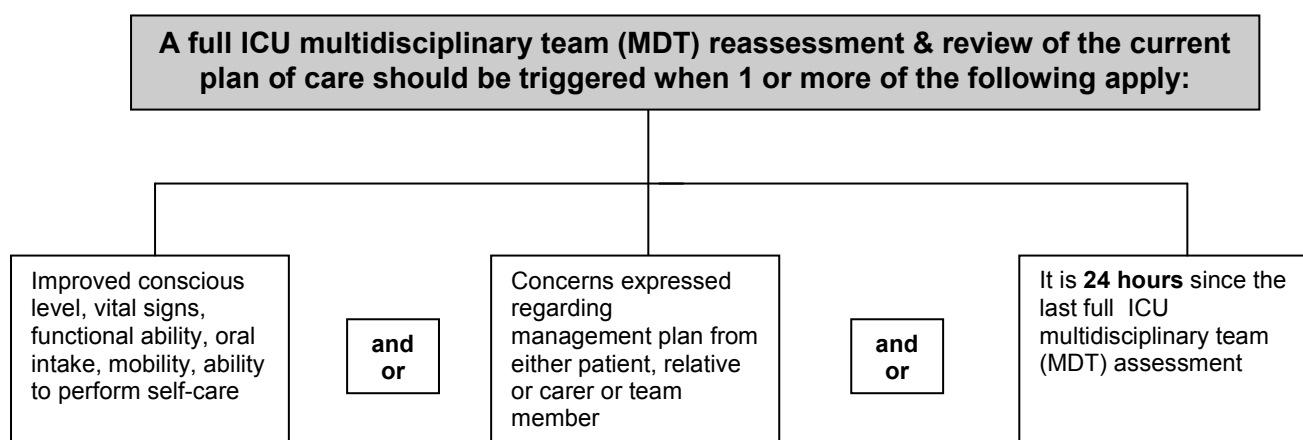
The patient must be formally assessed and each formal assessment documented every hour for the first 12 hours as indicated on the LCP ICU - each assessment is for a moment in time

For Example;

If you are making an assessment at **1200hrs** for each goal of care on the ongoing assessment you need to assess the patient for that moment in time – this is **NOT** an assessment over an hourly period since the last formal assessment at **1100 hrs**

You may have reviewed the patient on a number of occasions since the last formal assessment at **1100hrs** – there may indeed have been a number of variances (exception reporting) in care since the last formal assessment documented on the variance sheet. **Variance** is not a negative process but demonstrates the individual nature of a patient's condition based on their particular needs, your clinical judgement and the needs of the relative or carer.

If you make an assessment against a goal and the goal is achieved then record **A** for **Achieved** on the LCP ICU If for any reason there is a variance against a goal record a **V** for **variance** on the LCP ICU – then record the what variance occurred and why (what was the issue), what action did you take (what did you do about the issue), and the outcome of actions (what was the solution).



Always remember that the Specialist Palliative Care Team are there for advice and support

SECTION 3 - CARE AFTER DEATH

Goal 10 PATIENT CARE / DIGNITY

GOAL 10:	Last offices are undertaken according to policy and procedure
Rationale	<ul style="list-style-type: none"> ○ The patient is treated with respect and dignity whilst last offices are undertaken according to local policy and procedure. ○ All specific religious / spiritual / cultural rituals / needs should be considered at this time.
Required Behaviour	<ul style="list-style-type: none"> ● Treat the body with respect and dignity in line with any appropriate rituals and or belief systems. ● Local policy regarding the undertaking of last offices must be followed. ● Universal precautions and local policy and procedures including infection risk adhered to. ● Any spiritual / religious / cultural rituals needs of the patient / relative or carer must be respected. ● Organisational policy followed for the management of ICD's where appropriate. ● Organisational policy followed for the management and storage of patient's valuables and belongings.
Coding	Code Achieved if you have completed last offices according to local policy and procedure AND you have adhered to spiritual, religious, cultural rituals / needs of the patient / relative or carer
	Code Variance if for any reason you have NOT completed last offices according to local policy and procedure and you have NOT adhered to spiritual / religious / cultural rituals / needs of the patient / relative or carer A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.

GOAL 11 – RELATIVE OR CARER INFORMATION

GOAL 11:	The relative or carer can express an understanding of what they will need to do next and are given the relevant written information
Rationale	<ul style="list-style-type: none"> ○ The relative or carer must have a conversation with the healthcare professional backed up by written information to outline what the relative or carer will need to do next in respect of practical or legal tasks following the patient’s death.
Required Behaviour	<ul style="list-style-type: none"> • The healthcare professional must have a conversation with the relative or carer regarding what the relative or carer will need to do next • At this sad and challenging time retaining verbal information may be difficult and therefore the relative or carer must be given written information to support the conversation that has taken place <ul style="list-style-type: none"> ➤ Grieving leaflet ➤ “What to do after a death” booklet • It is important not to assume understanding but to check what the relative or carer has understood.
Coding	<p>Code Achieved if you have had the relevant conversation AND given an associated information leaflets.</p> <p>Code Variance if for any reason you have NOT had the relevant conversation AND/OR have NOT given an associated information leaflets</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 12.1 - 12.2

ORGANISATION INFORMATION

GOAL 12.1	The Primary healthcare team / GP is notified of the patient's death
Rationale	<ul style="list-style-type: none"> ○ The primary health care team must be informed of the patient's death as the patient is always registered under their care. ○ The primary healthcare team need to be notified of the patient's death so that they can: <ul style="list-style-type: none"> ➤ Support relatives or carers at this sad and challenging time ➤ Cancel any outstanding appointments for the patient
Required Behaviour	<p>The healthcare professional must contact the primary health care team and ensure that they are notified of the patient's death.</p> <p>In the ICU it would be appropriate to contact the GP practice - have a conversation where possible or leave a message or secure fax out of hours to inform the GP practice of the patient's death.</p>
Coding	<p>Code Achieved when you have notified the primary healthcare team / GP practice</p> <hr/> <p>Code Variance when you have NOT been able to notify the primary healthcare team / GP practice.</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

GOAL 12.2	The patient's death is communicated to appropriate services across the organisation
Rationale	<ul style="list-style-type: none"> ○ All personnel involved in the care of the patient must be informed of their death. This promotes a seamless and effective communication process to best support the bereaved relative or carer at this sad and challenging time ○ All services who have been involved in the patient's care must be made aware of the current status via the organisational IT systems in order to reduce any distress that could potentially be caused to a bereaved relative or carer at this time and into the future.
Required Behaviour	<ul style="list-style-type: none"> ● The healthcare professional / other personnel contacts the relevant services and departments e.g. bereavement office / general office / palliative care team / district nursing team / community matron to inform them of the patient's death ● The patient's death is entered on the organisations IT system
Coding	<p>Code Achieved when you have notified the appropriate services AND inputted the relevant information on the appropriate IT system.</p> <p>Code Variance when you have NOT been able to notify the appropriate services AND / OR inputted the relevant information on the appropriate IT system</p> <p>A coded variance must be accompanied by a written explanation on the variance sheet within the LCP ICU.</p>

LCP ICU Version 12 – list of goals

GOAL 1.1	The patient is able to take a full and active part in communication
GOAL 1.2	The relative or carer is able to take a full and active part in communication
GOAL 1.3	The patient is aware that they are dying
GOAL 1.4	The relative or carer is aware that the patient is dying
GOAL 1.5	The opportunity for organ/tissue donation is considered by the ICU MDT and the Specialist Nurse in organ donation has been contacted
GOAL 1.6	The clinical team have up to date contact information for the relative or carer as documented below
GOAL 2	The relative or carer has had a full explanation of the facilities available to them, and an ICU facilities leaflet has been given
GOAL 3.1	The patient is given the opportunity to discuss what is important to them at this time e.g. their wishes, feelings, faith, beliefs, values, organ donation
GOAL 3.2	The relative or carer is given the opportunity to discuss what is important to them at this time e.g. their wishes, feelings, faith, beliefs, values
GOAL 4.1	The patient has medication prescribed on a prn basis for all of the following 5 symptoms which may develop in the last hours or days of life
GOAL 4.2	Equipment is available for the patient to support a continuous infusion of medication where required
GOAL 5.1	The patient's need for current interventions has been reviewed by the ICU MDT
GOAL 5.2	The patient has a Do Not Attempt Cardiopulmonary Resuscitation Order in place
GOAL 5.3	Implantable Cardioverter Defibrillator (ICD) is deactivated
GOAL 6	The need for clinically assisted (artificial) nutrition is reviewed by the ICU MDT
GOAL 7	The need for clinically assisted (artificial) hydration is reviewed by the ICU MDT
GOAL 8	The patient's skin integrity is assessed
GOAL 9.1	Full explanation of the current plan of care (LCP ICU) is given to the patient
GOAL 9.2	Full explanation of the current plan of care (LCP ICU) is given to the relative or carer
GOAL 9.3	The LCP Coping with dying leaflet or equivalent is given to the relative or carer
GOAL 9.4	The patient's primary health care team / GP practice is notified that the patient is dying
GOAL 10	Last offices are undertaken according to policy and procedure
GOAL 11	The relative or carer can express an understanding of what they will need to do next and are given the relevant written information
GOAL 12.1	The Primary healthcare team / GP is notified of the patient's death
GOAL 12.2	The patient's death is communicated to appropriate services across the organisation

LCP ICU version 12 – list of goals

GOAL A	The patient does not have pain
GOAL B	The patient is not agitated
GOAL C	The patient does not have respiratory tract secretions
GOAL D	The patient does not have nausea
GOAL E	The patient is not vomiting
GOAL F	The patient receives respiratory support according to their individual needs
GOAL G	The patient does not have urinary problems
GOAL H	The patient does not have bowel problems
GOAL I	The patient does not have other symptoms
GOAL J	The patient's comfort & safety regarding the administration of medication is maintained
GOAL K	The patient receives fluids to support their individual needs
GOAL L	The patient's mouth is moist and clean
GOAL M	The patient's skin integrity is maintained
GOAL N	The patient's personal hygiene needs are met
GOAL O	The patient receives their care in a physical environment adjusted to support their individual needs
GOAL P	The patient's psychological well-being is maintained
GOAL Q	The well-being of the relative or carer attending the patient is maintained