



**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
Bae Abertawe  
Swansea Bay University  
Health Board



<b>Meeting Date</b>	<b>25 October 2022</b>	<b>Agenda Item</b>	<b>4.1</b>
<b>Report Title</b>	<b>Quality and Safety – END OF LIFE CARE</b>		
<b>Report Author</b>	Dr Sue Morgan Consultant Specialist Palliative Care & Health Board Clinical Advisor for End of Life Care Helen Griffiths, Corporate Head of Nursing		
<b>Report Sponsor</b>	Gareth Howells Director of Nursing & Patient Experience		
<b>Presented by</b>	Dr Sue Morgan, Clinical Advisor for End of Life Care		
<b>Freedom of Information</b>	Open		
<b>Purpose of the Report</b>	To up-date the Quality and Safety Priorities Programme Board on activity around the End of Life Care Quality and Safety Priority		
<b>Key Issues</b>	<ul style="list-style-type: none"> <li>Engagement across all service groups and all health professional groups</li> </ul>		
<b>Specific Action Required</b> <i>(please choose one only)</i>	<b>Information</b>	<b>Discussion</b>	<b>Assurance</b>
	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
<b>Recommendations</b>	Members are asked to: “live” the HB’s core value – High quality end of life care.		

## 1. INTRODUCTION

The purpose of the report is to update the Quality and Safety Priorities Programme Board on activity around the End of Life Care Quality and Safety Priority.

End of life care is defined as care in the last year of life, and includes care of the dying person and care in the last days of life.

The priorities of the dying person have been identified as:


- I. This possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- II. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- III. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- IV. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- V. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Approximately 1% of the population dies each year, and it is possible to anticipate the death of more than three quarters of those who die, due to chronic progressive organ failure, frailty or malignant disease. Over the next 10-15 years it is estimated that the number of people dying across Swansea bay UHB will increase by 25% and the number of people requiring palliative care will increase by 42%.

Swansea Bay UHB has been highlighted as an outlier (below standard) in the last round of the National Audit of Care at End of Life, and a majority of death happen in the hospital setting, with active, invasive treatments continuing to within a few

hours of death, even when there has been limited sign that physiological recovery is likely for days. Thus there is limited capacity to support the patient and those important to them during this transition and to address the five priorities of the dying person..

Change the last year of life from this												
12 Mth	11 Mth	10 Mth	9 Mth	8 Mth	7 Mth	6 Mth	5 Mth	4 Mth	3 Mth	2 Mth	1 Mth	Last days
												Admitted to hospital with expectation "getting better"
												Recognising dying ?
												Check understanding of condition/disease (if time)
												Identifying what is important patient and family (if time)
												Preferred place of care (if time)
												If time: Discussion re limitation of treatment; Preparation for what dying looks like
												DNACPR ?
												Stopping burdensome interventions ?
												Family distressed – not expecting "not get better"
												Family "angry" and taking up lot of time to understand /significant grief
Significant proportion of people with chronic advanced conditions/multiple comorbidities, currently												



## To more like this

12 Mth	11 Mth	10 Mth	9 Mth	8 Mth	7 Mth	6 Mth	5 Mth	4 Mth	3 Mth	2 Mth	1 Mth	Last days
Check understanding of condition/disease Prepare for what changes may be expected										Check		Check understanding of condition/disease
Identifying what is important to patient (and family)										Check		Check what is important to patient and family
Preferences place of care/death										Check		Check preferred place of care
Start discussion re limitations of treatment										Revisit		Revisit limitations of treatment
			Start talking about likely benefits and burdens of treatments options, including attempt at CPR, vs treating reversible causes of deterioration							DNACPR Preparation for what dying might look like		
				Recognise deterioration despite optimum treatments							Uncertainty	Recognising dying
What we could achieve for majority of chronic advanced conditions/multiple comorbidities.....										Identify treatments that may not add but may cause burden		Stopping burdensome interventions Assess for common symptoms in last days of life Plan of care specific to last days
												Family and patient prepared. Less overall distress Bereavement less complicated



## **2. BACKGROUND**

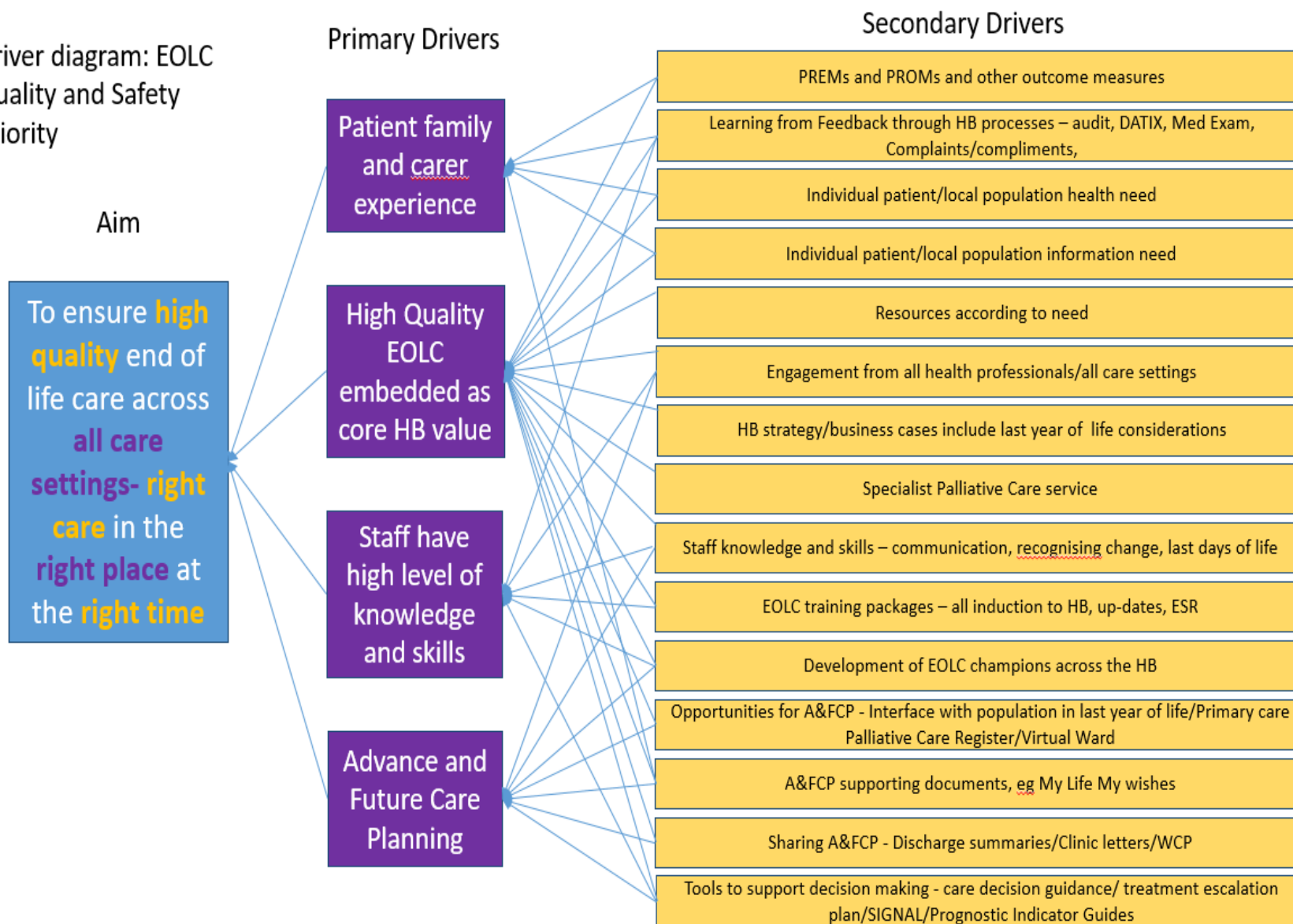
End of life care is one of Swansea Bay UHB's the top five priorities. The aim of this priority is to ensure that the population of Swansea Bay UHB, and people receiving care in the hospitals within Swansea Bay UHB receive the right care at the right time in the right place during the last year of life.

To achieve that the patient and those important to them should be at the centre of all clinical activity, with high quality end of life care being embedded as a care health board value. Key to this is that staff are supported to gain a high level of knowledge and skills to support people in the last year of life, including supporting the population to undertake advance and future care planning.

There is a committee with representation from each service group, Quality Improvement Team and digital services, which meets on a monthly basis, with one meeting each quarter incorporated into the HB's Palliative and End of Life Care Steering Committee.

Driver Diagram for the End of Life Care Quality and Safety Priority

Driver diagram: EOLC  
Quality and Safety  
Priority



## **Change Ideas/Actions Required**

### **➤ Patient experience**

- Collation and sharing of learning from all sources of patient/carer feedback
  - Learning from Deaths panel
  - Complaints
  - Compliments
  - Care After Death Team,
  - NACEL,
  - Internal audit
- Engagement with NACEL audit
- All Wales – PROMs
- Scoping current end of life care provision across all parts of HB, including third sector

### **➤ Embedding high quality end of life care as a care HB value**

- Inclusion of consideration of last year of life in **all HB strategy** /guidance/business cases
- HB leads “promoting” end of life care as Q&S priority for all staff
- HB training plan with minimum requirements for
  - each professional group
  - Each service group
- Scoping gaps in meeting end of life care needs
  - WAST
  - In-house
  - (Swansea University)
- Annual Communications plan eg, monthly focus
- HB public web page around end of life care
- Regular podcast episodes raising awareness of Care in the last year of life strategy

➤ **Education/Training**

- EOLC Champion Programme
- EOLC included in all HB induction/up-date programmes
- EOLC training on ESR
- EOLC Focus Months on identified wards providing patient and staff training – Quality Assurance and Quality Improvement elements to programme
- EOLC Champion Forum discussion group for EOLC champions
- Develop and agree HB training plan for all clinical staff and non-clinical staff
  - Difficult Conversation
  - Advance and Future Care Planning
  - Recognising dying
  - Treatment escalation plans
  - Use of Care Decision guidance to support care in last days of life
  - Prediction of patient need in relation to prognostication

➤ **Advance and Future Care Planning**

- Include prognostication and appropriate prompts for A&FCP into SIGNAL
- Include A&FCP conversations in
  - WCP,
  - Discharge Summaries,
  - Clinic Letters
- Re-introduction and standardisation of Primary Care Palliative Care Register
- Include prompt – “suitable for palliative care register” in discharge summaries and clinic letters



**Measures to focus direction/understand patient journey**

- Patient flows / Patient need
- Resource requirements/demands with current patient flows
- Current resources, including third sector
- Number of referrals to specialist palliative care
- Number of patients on GP Palliative Care Register
- Number of fast-track discharges from hospital to community – for care in the last days of life
- Deeper review of patient journey when had three hospital admissions in last year of life
- Number of investigations in the last days/hours of life (more relevant to longer length of hospital admissions as last episode of care)
- Number of patients dying on active treatment
- Audit of care in the last days of life in secondary care

**Measures to monitor progress****Long-term**

- Number of advance and future care plans recorded
- Symptom burden over last year of life – physical/emotional/spiritual/social – PROMs
- Patient/Carer experience – PREMs/complaints/compliments/NACEL
- Place of death
- Patients preferred place of death
- Proportion of population achieving preferred place of care
- Number of complaints/compliments of care in last year/months/weeks/days of life (Datix/Medical Examiner)
- Themes of complaints/compliments of care in last year/month/weeks/days of life (Datix/Medical Examiner)
- Proportion of staff trained and competent in supporting communication, recognising dying and delivering care in the last days of life

### **3. GOVERNANCE AND RISK ISSUES**

“How people die lives on in the memories of those left behind”

End of life care is not just about helping people live as long as possible, but instead delivering care to meet, where possible, the priorities of the individual person.

#### **3.1 End of Life Care embedded HB value**

Working on it.....

Whilst End of Life Care has been recognised as a Quality and Safety Priority, there is a significant amount of work required to transform how end of life care is delivered in Swansea Bay UHB to a standard that we might want for our family or ourselves.

It is important that all HB strategy has a focus on the support provided to people who may be in the last year of life, supporting them to be involved in understanding what is happening to them, and what all the options are around treatment. In the same way, it is impossible to deliver high quality care without understanding what is important to the individual you are supporting.

To be able to live this priority, that high quality end of life care is a core value of Swansea Bay University HB, all induction programmes should emphasise that value, and its importance would be made visible by mandated training around end of life care.

Other examples where high quality end of life care is a core value for us would include consideration of the dying person during the prioritisation of the single rooms; the transfer of dying patients out of A&E to a more suitable environment; allowing a dead person to remain in a single room until they have been seen by those important to them.

Work is required to ensure that all service Groups and all Departments identify with this core value.

### **3.2 Digital intelligence**

Understanding patient pathways during the last year of life is key to understanding where focus of support is required. Work is underway to:

- Understand current data available to the HB, and bring this into the HB with creation of dashboards to provide detail “at a glance”
- Gaps in data and identifying processes to secure those data.

Work is currently being undertaken to understand

- the characteristics of patients who die within the Accident and Emergency setting
- delivery of palliative and end of life care by community/district nursing teams
- place of death by age; comorbidities; GP cluster; Specialist Palliative Care
- use of Health Services by patients in the last months of life
- discussions around advance and future care planning
- use of the care decision guidance to support care in the last days of life
- delivery of training around end of life care, recognising dying, use of the care decision guidance, communication skills, advance and future care planning

### **3.3 National Audit of Care at the End of Life (NACEL)**

The National Audit of Care at the End of Life (NACEL) is commissioned by the Health Care Quality Improvement Partnership on behalf of NHS England and the Welsh Government. The overarching aim of the NACEL Audit is to improve the quality of care of people at the end of life in acute, Mental Health and Community hospitals. The audit monitors progress against the five priorities for care.

The findings of the last NACEL audit indicate that Swansea Bay University Health Board is achieving less than the National average in all aspects of care at end of life. It indicates that there may be delays in recognising that someone is dying, and

therefore limited opportunity to address the five priorities of the dying person, and those important to them. The consequences of this are that the:

- the clinical team is
  - not able to meet the priorities of the dying person
  - not able to set appropriate treatment escalation plans to support decision making
- dying person is
  - not able to be involved in decision making around their care;
  - unable to have meaningful conversation with those important to them (such as Thank you, Forgive me, I forgive you, I love you);
- those important to the dying person are not prepared for the death, and this can result in complicated grief.

The Health Board needs to be supported to modify the focus of care, including acknowledging when someone is sick enough to die. It is encouraged to advocate greater use of advance and future care planning early in the patient journey and the greater use of care decision guidance to support care in the last days of life.

Data is currently being collected for the current round of the audit and will include;

1. Organisational Level data
2. Case Note Review
3. Quality Survey – asking family and carers experience (no contribution 2020-21)
4. Staff Reported Measure (no contribution 2020-21)

Nominations to support the audit has been received from nursing staff, there have been no nominations received from Medical Teams.

The Steering Committee is keen to achieve traction in general around Medical & Therapy engagement as well as Nursing

### **3.4 Care Decision Guidance for Care in the Last Days of Life.**

Performance in the National Audit of Care at the End of Life (NACEL) indicates that clinicians are late to identify/acknowledge when people are dying in Swansea Bay Hospitals. Almost a third of people who died were not identified as dying until the last twelve hours of life. The late acknowledgement of people dying means that there is insufficient time for the patient and family to both have those conversations and adjust to that news before the individual has died. For the majority of these patients there was clear documentation that the person's condition was continuing to deteriorate, despite optimal treatment, over the previous week or more.

With the late acknowledgement that someone is dying there is little opportunity to address the five priorities of the dying person.

The All Wales Care Decision Guidance to support care in the last days of life focuses on the five priorities of the dying person (One Chance to Get it Right). Earlier acceptance that a person is sick enough to die and wider use of the Care Decision Guidance to support care in the last days of life would go a long way to improve the demonstration of all aspects of care in the last days of life.

The HB's system of reviewing safeguarding around end of life (EMRA) provided a platform to monitor the use of the Care Decision Guidance within the secondary care setting, and with the transition to the Medical Examiner System the Health Board is challenged to identify other methods of collecting these data, across all care settings. The Health Board has linked with the Medical examiner around accessing the Care Decision guidance information.

Individual wards have been supported in both the recognition of dying and the use of the care decision guidance. This work will need to be continued, and is likely to require recurring input to revisit this essential component of care at the end of life.

### 3.5 Advance and Future Care Planning

Engagement in advance and future care planning has been shown to

- Enables greater autonomy, choice and control - respects the person's human rights, enabling a sense of retaining control, self-determination and empowerment.
- Improves the quality of end of life care provided for individuals and populations
- Enables deeper discussions and consideration of spiritual or existential issues, reflection on meaning and priorities and encourage resilience and realistic hope.
- There is greater concordance with wishes if they have been discussed, for example more people die in their preferred place of death
- Enhanced proactive decision making reduces later burden on family and relieves anxiety
- Enables better planning of care, including provision by care providers
- Reduced unwanted or futile invasive interventions, treatments or hospital admissions, guiding those involved in care to provide appropriate levels of treatment
- Greater satisfaction, reduced anxiety and depression in bereaved relatives
- Economically cost-effective in reducing costs
- The process can itself be therapeutic and enable resolution of relationships

To ensure the population of Swansea Bay University Health board (HB) is equipped to engage in decision making around their care and priorities in the last year, months, weeks and days of life (optimising the opportunity to receive the right care at the right place at the right time), greater clinical engagement in advance and future care planning is essential.

Swansea Bay has recently introduced My Life My Wishes tool to support patients (and those important to them) to consider and identify what is important to them as they go through their health journey. The Virtual Wards have provided the impetus for including this tool within our resources and wider roll out of this tool is planned.

The Health Board is also challenged to identify processes to record and share the advance and future care planning conversations across all teams supporting patients. The ability to capture performance is restricted as currently the only mechanism is via the Welsh Clinical Portal. The Welsh Government examines the information from the Welsh Clinical Portal every quarter and reports back to the Health board. There is a plan to link with Primary Care Systems with Welsh Portal to

automate the collection of data, this is not currently operating. There is further work to be undertaken in both Primary & Secondary Care to promote Advance & Future Care Planning and the recording/sharing of information.

### **3.6 End of Life Education & Training**

Education and training around supporting patients who are in the last year of life (and those important to them) is an integral part of the quality and safety priorities, preparing our staff to have the tools to support patients and those important to them to navigate the roller-coaster ride of last year of life. The End of Life Care Champion Programme is ongoing there has been good attendance and engagement from nursing. Further work is required around Medical engagement. Care Home representatives have also been invited to attend the sessions.

Work is being undertaken to develop a training video on end of life care for inclusion in induction programme for the new Doctors.

Work is also in place to fine tune the data capture for the training undertaken by the Parasol Team. It is expected that this will then form the foundation for reporting back to the HB and Service Groups, etc, of training activity. It will also assist in quantifying the training being delivered by the team to support the Quality and Safety Priority. This work is reported as part of the quality priorities.

The staff experience of delivering care in the last days of life is being explored through the NACEL audit this year.

#### **Challenges**

Promotion of training around recognising dying and care of the dying person across the medical teams, including the use of the care decision guidance to support decision making and communication in the last days of life and advance and future care planning needs of people who may have less than a year to live.

Identification of communication skills training to support

- Difficult Conversation
- Advance and Future Care Planning
- Treatment escalation plans

It is also recognised that the HB has a role to support the public to understand end of life care, and the role of advance and future care planning, preparation for treatment escalation plans, and early work is being undertaken to develop a public facing HB internet page discussing these key issues.

### **3.7 Care After Death**

The Care After Death Service now has a full team and provides support to families seven days a week for care after death and bereavement support. Within the hospitals the Team is automatically informed of a death and offer support to those important to the person immediately. It is now also possible to refer families of people who have died within the community setting to the Care after Death Service.

The Care After Death Service has been instrumental in preparing the ground for the NACEL Quality Survey, identifying family and friends who are willing to support the Survey.

The Team has supported the roll out of the role of the Medical Examiner, and is instrumental in supporting the process around certification of cause of death.

### **3.8 Patient / family experience**

The End of Life Care Quality and Safety Priority recognises the importance of the voice of the patient/carer in ensuring services are delivered according to what is important to them. This is an element of the priority that is to be fully established. In the meantime, scrutiny of data that is available to the HB is being undertaken.

The scrutiny of safeguarding and quality assurance round deaths within the hospital setting has moved from the health board Mortality Review process to independent scrutiny by the Medical Examiners Service. For each death within the hospital setting (Morriston and Singleton currently, with plans to expand to the other hospitals and then community) the Medical Examiners Service reviews the clinical record, and discusses the case with both the clinicians and the patient's family. Where there are issues identified (both safeguarding and quality of care) these are referred to the Health Board's 'Learning from Deaths' scrutiny panel, for further review.



The Committee was informed that it has been a year since the multi-professional 'Learning from Deaths' scrutiny panel was implemented. It meets weekly to review the referrals back from the Medical Examiner.

Relatively few referrals are because the Medical Examiner has concerns with the clinical care offered. However, as also identified through Datix and complaints to the HB, quality of communication is a recurring theme of the referrals, across several domains. Further work is being undertaken to more deeply understand opportunities to address the issues raised by the Medical Examiner and to support learning across the HB.

Data is available from feedback through the Care After Death team, and Carer Experience is a component of the current round of the NACEL audit, and is in the data collection phase.

Review of complaints around end of life care is agenda'd for the next few months.

### **3.9 National Programme Board End of Life Care Funding**

The Health Board is preparing a response in relation to the 2021-2022 & 2022-2023 funding allocation of £72K. The allocations have been in place since 2016. The response will be sent to the NHS Collaborative Programme Lead.

Understanding the patient journey, current need and gaps in meeting needs will enable services to develop business cases for such funding.

## **4 FINANCIAL IMPLICATIONS**

As outlined in the report.

Anticipation that undertaking good care in the last year of life, with advance and future care planning will add value to patient care. With greater focus on what is important to the patient there is significant potential to reduce investigations, invasive procedures and treatments that the patient/individual as the person become less able to benefit from those interventions.

If care in the last year of life is done differently, with a focus on communication and advance and future care planning then the other cost of patient and family distress and professional time taken to respond to complaints could be significantly reduced.


There is potential for this to be mapped out and calculated – value based health care.

## 5.RECOMMENDATION

The Quality and Safety Board are asked to note the information outlined in the paper, and members promote the inclusion of end of life care considerations before approving any HB strategy/documentation.

Extend mandatory training to include end of life care

Governance and Assurance		
Link to Enabling Objectives (please choose)	Supporting better health and wellbeing by actively promoting and empowering people to live well in resilient communities	
	Partnerships for Improving Health and Wellbeing	<input checked="" type="checkbox"/>
	Co-Production and Health Literacy	<input checked="" type="checkbox"/>
	Digitally Enabled Health and Wellbeing	<input checked="" type="checkbox"/>
	Deliver better care through excellent health and care services achieving the outcomes that matter most to people	
	Best Value Outcomes and High Quality Care	<input checked="" type="checkbox"/>
	Partnerships for Care	<input checked="" type="checkbox"/>
	Excellent Staff	<input checked="" type="checkbox"/>
	Digitally Enabled Care	<input checked="" type="checkbox"/>
	Outstanding Research, Innovation, Education and Learning	<input checked="" type="checkbox"/>
Health and Care Standards		
(please choose)	Staying Healthy	<input checked="" type="checkbox"/>
	Safe Care	<input checked="" type="checkbox"/>

	Effective Care	☒
	Dignified Care	☒
	Timely Care	☒
	Individual Care	☒
	Staff and Resources	☒
<b>Quality, Safety and Patient Experience</b>		
Providing high standard of care for people in the last days of life is a core value of the Health Board. The Palliative and End of Life Steering Committee will ensure that the voice of patients and those important to them are at the centre of service planning and delivery. This will support clinicians to deliver care in accordance with what is important to the person, and ensure that the HB designs services to explore advance and future care planning with the population it serves.		
<b>Financial Implications</b>		
Funding has been agreed for the Quality & Safety Priorities.		
<b>Legal Implications (including equality and diversity assessment)</b>		
To meet the required standards in line with Welsh National Clinical Framework and other key documents.		
<b>Staffing Implications</b>		
Staffing implications are outlined where appropriate		
<b>Long Term Implications (including the impact of the Well-being of Future Generations (Wales) Act 2015)</b>		
<ul style="list-style-type: none"> <li>The objective of the End of Life Care Quality and Safety Committee is to bring expertise from all parts of the Health Board and its collaborators to develop and deliver care based on current best practice.</li> </ul>		
<b>Report History</b>	No previous reports	
<b>Appendices</b>	 EOL Quality Priorities TOR.docx	

