Title of Report	Palliative & End of Life Care (EOLC) highlight report
Executive Summary	This paper will provide an update of the current Palliative & EOLC initiatives across the organisation
Actions requested	Update for Joint Health Overview and scrutiny Meeting – August 2016

Corporate Objectives supported by this paper:

1. To provide high quality, evidence based, safe services delivered in a personal and compassionate way
2. To modernise, transform & integrate services across our sites
3. To improve productivity & reduce variation
4. To engage & support patients, carers, volunteers, staff, public & communities in our work
5. To create an environment so staff choose to work with us, sickness absence is reduced/morale increased
6. To be an influential organisation working in partnership with others across the health & social care system to improve the health of the population.

Risks:

- Inability for sole delivery of the EOLC agenda and to meet the educational requirements of all health care professionals working across Pennine Acute Hospitals Trust (PAHT) by the EOLC/Specialist Palliative Care team due to small workforce.
- Inability to provide seven day week working, due to inadequate staffing establishments, for Specialist Palliative Care across the hospital sites. This is a national requirement. This risk has been placed on the Divisional risk register for Integrated and Community Services and was discussed at the Divisional Quality & performance committee.
- Carers not appropriately supported through the bereavement phase due to no dedicated service, therefore a business case has been developed and submitted to the Deputy Chief Nurse. Following this more detailed work is taking place around service modelling/re-design. Visits now undertaken with the patient experience lead to look at other organisations bereavement service models. Following this a paper outlining the preferred model is to be submitted.

Public and/or patient involvement:

- User representation on the Trust palliative & EOLC Steering Group
- Patient/carer focus groups to inform the development of the strategy
- Bereavement survey feedback
- Links with the Pennine Patient Partnership Group
- Patient stories
- Carer involvement at previous EOLC showcase events

Title of Report	Palliative & End of Life Care (EOLC) highlight report

Resource implications:

- Resource required to fund seven day week working for Specialist Palliative Care which is being considered at Divisional level, this will be dependent upon the outcomes following the piloting of this.
- Potential resource required from staffing & estates perspective for the development of a trust bereavement service. This is currently under review with a business case being developed as above.
- Initial funding for EOLC resources including canvas property bags, jewellery pouches, hair lock pouches, comfort packs has initially been secured via the Specialist Palliative Care endowment fund. All items have now arrived and the packs are being put together by Newbridge student future finder's volunteers. These have now been distributed to ward areas with guidance for use. Permanent funding for this will be required.

Communication:

- Via Chief/Deputy Chief Nurse supporting EOLC agenda
- Quarterly EOLC report now to be submitted via the Safety Committee
- Feedback via Divisional Q&P Committees and Divisional structures
- Via Patient Experience Committee

Have all implications been considered?	**YES**	**NO**	**N/A**
Assurance	✔		
Contract			✔
Equality and Diversity	✔		
Financial / Efficiency	✔		
HR			✔
Information Governance Assurance	✔		
IM&T	✔		
Local Delivery Plan / Trust Objectives	✔		
National policy / legislation	✔		
Sustainability	✔		

Name	Alice Davies
Job Title	Macmillan Associate Lead Cancer & Palliative Care Nurse
Date	30/8/16
Email	Alice.davies@pat.nhs.uk

Palliative & End of Life Care (EOLC) highlight report

1. Introduction

- The EOLC phase as in accordance with the North West EOLC model includes the period from advancing disease (pre-dicted12mths to live) through to time of death & into bereavement.
- There are currently a variety of national recommendation's and guidance in relation to palliative & EOLC. Significant improvements are required here at PAHT to optimise the patient/care experience at the End of Life.
- This report will provide an overview of the current Palliative and EOLC initiatives and the progress to date.

2. Strategic Context

Detailed below are recent palliative and EoLC publications. The initiatives described throughout this report will significantly contribute towards achievement of these recommendations and guidance.

Title	Overview
Care of dying adults in the last days of life (December 2015 NICE)	This guidance provides recommendations to help healthcare professionals to recognise when a person is entering the last days of life or may have stabilised or be improving even temporarily; to communicate and share decisions respectfully with the dying person and people important to them; and to manage hydration and commonly experienced symptoms to maintain the persons comfort and dignity without causing unacceptable side effects.
Ambitions for palliative and end of life care (September 2015, Department of Health)	This publication details an overarching vision and six ambitions that health professionals should endeavour to achieve. Each of the six ambitions includes a statement to describe the ambition in practice, primarily from the point of view of a person nearing the end of life. The initiatives detailed in the main body of the report would further progress achievement of these ambitions.
Dying without Dignity (May 2015, Parliamentary and Health Service Ombudsman)	This report identifies key themes. These themes enable area's that require further improvement in relation to the quality of EOLC provided. The themes include not recognising that people are dying, poor symptom control, poor communication, inadequate out-of –hours services, poor care planning and delays in diagnosis and referrals for

Title	Overview
	treatment. Again all current work involves addressing all of these areas.
One Chance to Get it Right: how health and care organisations should care for people in the last days of life (June 2014, Department of Health)	The alliance has developed five Priorities for Care, which set out the standards of care that dying people and their families should expect to receive. Across the organisation we are implementing the five principles as part of the individualised plan of care and alongside educational initiatives.

3. PAHT Palliative & End of Life Care Update

3.1 Individual plan of Care and Support For the Dying Person plan and Communication Diary

Following the national review and withdrawal of the Liverpool Care Pathway the Leadership Alliance for the Care of Dying People established key Priorities For Care when it is thought that a person may die within the next few days or hours. It was recommended that organisations adopt these principles in the form of an individual care plans.

As an organisation we worked in partnership with the Strategic Clinical Network to develop documentation to support implication of these principles of care. This document has been piloted across the transform wards and is now fully implemented across the trust including the use of the communication diary.

The use of the priorities of care within this plan will provide assurance that every patient who is in the last days of life across the organisation with receive the best possible quality of EOLC and that the carers of these patients will be appropriately supported.

Monthly monitoring of the use of the individual plan of care for the dying person is taking place and reported via the Trust EOLC steering group. The EOLC team have recently undertaken an audit of all the adult deaths that have taken place in the last week of June, in relation to the application of the principles of care. Results will be available within the next three weeks.

3.2 Palliative & EOLC (incorporating Bereavement) Strategy

This has now been fully ratified at Trust Board. Engagement and input has now been obtained from:

Nursing & Midwifery Committee
Pennine Patient User Partnership group
PAHT palliative & EOLC steering group
End of life Care CCG leads across localities of PAHT
Specialist Palliative Care service & Governance group

Three focus groups for wider community engagement from a variety of support groups took place October 2015. The issues raised from these groups have been incorporated into a patient feedback action plan as part of the strategy and monitoring of this progress towards this will take place via the Palliative and EOLC Steering Group.

Following Board of Director approval, the Palliative and EOLC strategy and a variety of current EOLC initiative across the Trust have been now launched at EOLC showcase events.

3.3 PAHT Palliative & EOLC Steering Group

This is fully established with agreed Terms of Reference & reporting arrangements. This Meeting is being chaired by Deputy Chief Nurse/Lead Clinician (Dr Iain Lawrie, Consultant in Palliative Medicine). This group oversees the implementation of the Trust Palliative & EOLC (incorporating Bereavement) Strategy.

3.4 National Hospitals EOLC Audit

The data collection has now taken place and the national report has recently been published. Some of the key findings from the clinical patient case note review are as follows:

Recognition of dying

- 93% of patients whose death was predictable had documentation that they would probably die. In 76% of cases, a senior doctor was involved in the recognition of dying. For half the patients, recognition of dying occurred within 5 days after admission and for half the patients this occurred less than 34 hours before death.

Communication and treatment decisions

- Only 4% (415/9302) of patients had documented evidence of an advance care plan made prior to admission to hospital
- UDNACPR order in place for 94% of patients notes at the time of death. Where sudden death excluded, discussion about CPR by a senior doctor with the patient was recorded in 36%. Overall, for 16% there was no reason recorded why a discussion did not take place.

Communication with people important to patient

- In 38% of cases, there was documented evidence in the last episode of care that the patients' needs had been discussed with the people important to them.
- There was documented evidence of care and support of the patient's family at the time of and immediately after death, in 65% of cases with wide variation between different sites.

Individual plan of care- symptom control

- 83% of patients had had a holistic assessment with a view to making an individual plan of care
- There was documented evidence that pain was controlled in 79% cases, agitation in 72%, noisy breathing/death rattle in 62% and nausea/vomiting in 55%

Drinking and eating

- In the last 24hrs of life there was documented evidence that: in two- thirds of cases the patient's ability to drink had been assessed. 39% of patients were documented as drinking and in 45% of cases that the patient had been supported to drink.
- 18% of patients had a nil by mouth order in their last 24hrs
- 71% of cases, there was documented evidence that the patient had an assessment regarding the need for clinically assisted (artificial) hydration (CAH) at any time between the final admission and death.
- CAH was in place during the last 24hours before death in 43% of patients.

Spiritual care

- There was documented evidence of discussion regarding the patient's spiritual/cultural/religious/practical needs with 15% of patients who were capable of participating in such discussions.

The national results have only been provided collectively across all the hospital sites of PAHT; however a breakdown of this per site has been requested from the national team. To date this has not yet been received. The findings from this will be presented and disseminated widely during the next couple of months. Following detailed analysis of the results an action plan has been drafted and will be presented and monitored via the EOLC steering group.

We are also in the process of engaging with IM&T in relation to some prognostic guidance around EOLC that can be available on the intranet. We have now producing some small pocket cards for clinical staff detailing the Priorities for Care and Support for the Dying person. Laminated A4 sheets detailing the priorities for care are now placed within agreed clinical areas. EOLC resource folders are now in place on all relevant clinical areas.

3.5 National EOLC Transformation Programme

As an organisation we registered at National level to take part in the National EOLC Transformation Programme. This entails transforming end of life care services and working to 'The route to success - improving quality end of life care in acute hospitals' (2010) - based on the National End of Life Care Strategy (2008). The aim of this is to provide excellent end of life care to all patients and carers, using a structured approach, with set standards and outcomes. Two wards on each hospital site have now undertaken the full programme. All base line data was previously collected and includes audits around case notes, staff skills and knowledge, mortuary transfer times and a bereavement survey. Post programme data is now available and the post programme report and action plan are in place. The implementation of these will be monitored by the Palliative & EOLC Steering Group. The rollout of the second cohort is now underway. Base line audit has now taken place.

3.6 Policies/guidelines/leaflets

Development of a variety of palliative and EOLC policies/guidelines has taken place. We currently have seven Palliative and EOLC policies/guidelines available across the trust. The Pain and Symptom control guidelines have now been reviewed as the Strategic Clinical Network have just reviewed and revised these, which we have adopted. The Rapid Transfer Pathway Policy is now finalised. These documents have all been fully ratified and uploaded onto the trust intranet. There is also availability of ten EOLC patient/carer leaflet. We have also developing a rapid Transfer Leaflet for patients going home to die which is available on the intranet.

Work has been undertaken with North Manchester community colleagues to ensure all acute end of life care policies include relevant community information as one joint policy. All updated policies now have appropriate community additions.

3.7 EOLC volunteers

SevenTrust volunteers have been trained to work as EOLC volunteers on the transform wards. The volunteers have identified key roles and responsibilities, which primarily are supporting the patients and carer with basic care such as assisting with drinking following advice from Nursing staff, washing face / hands and combing hair, sitting with the dying patient to allow carers a comfort break if required, explaining the facilities available for carers and where refreshments cab be obtained. The EOLC team are currently in the process with the volunteer's manager to further progress this initiative.

Further recruitment is to take place within the next six months, to further expand this provision to enable further role out across the Trust.

3.8 SPC seven day week working

North Manchester community palliative and supportive care service currently provide this provision. All hospital sites of PAHT are non-compliant with this at present. There is a small pot of funding to pilot this. Currently no permanent funding secured for the provision of seven day week working for Specialist Palliative Care teams across the hospital sites. This risk has been placed on the Division of Integrated and Community Services risk register and was discussed at the Divisional Quality & performance committee. The plan is to pilot seven day week working at NMGH, aiming to commence October/November 2016.

3.9 Electronic Palliative Care Co-ordination Systems (EPaCCS)

The data field requirements for EPaCCS have been incorporated within SPC data base. The clinical portal will have a platform for EPaCCS. Further role out of EPaCCS is dependent on commissioning via local CCGs to enable transfer of information between key stakeholders. North Manchester CCGs have funded the development of EPaCCS and are working towards implementation this co -ordination system. A North East Sector project has now been commissioned, (PAHT leading this work) to implement a Medical Interoperability Gateway (MIG), this will be a platform for EPaCCS implementation.

3.10 Education & Training

Previous palliative and EOLC rolling education programme revised and updated which includes identifying patients approaching end of life and planning of their care, priorities for care and support for the dying person including emotional, spiritual and religious needs, care at time of death and into early bereavement, communication in Palliative Care incorporating: unified Do Not Attempt Cardiopulmonary Resuscitation (uDNACPR) and rapid transfer, palliative care emergencies, nutrition & hydration in palliative patients and pain and symptom control at end of life. The topics are delivered within a modular basis over two days, three times a year rotating over sites. The revised programme started in November 2015. Attendance for training is recorded via the training and development department and the use of the standard trust evaluation forms.

Previous programmes have evaluated well within the last year 310 nursing staff, 42 medical staff, 16 Allied Health Care professional have undertaken formal training in EOLC. This only captures the training accessed via the education centres. We are working with the Learning and Development departments to capture the ad hoc EOLC education that is delivered within the clinical areas. We also adopted a national EOLC e-learning programme across the organisation; figures can now be accessed for those who have undertaken the modules.
There is a Palliative and EOLC link member's one day programme across the trust which is held three times a year. Communication skills' training is provided across the Trust in the form of Sage and Thyme training. The End of Life Care Team also have a session on the Care Certification training once a month, an annual session on the Cadets training and the Specialist Palliative Care Team support the Consultants in Palliative Medicine to provide training to the FY1 and FY2's on an annual basis. The End of Life Care Team has recently piloted training for ancillary staff. The evaluation demonstrated the sessions required need to be tailored to each individual staff group in

which the End of Life Care Team will be revisiting. We have a national EOLC programme available via e-learning within the organisation called e-ELCA (EOLC for adults). There now also an e-learning package developed, for clinical staff to undertake training around the EOLC priorities of care and the individualised EOLC plan.

3.11 EOLC Standards for Clinical Areas

Developed as part of a 'listening into action event', patient/carer feedback and national guidance. Some of these include: Utilise butterfly symbol for patients at end of life, open visiting time for loved ones, relatives area available and each ward has access to quiet area. Every patient at end of life is offered emotional support and spiritual care, patients who are on an Individual Plan of Care and Support for the dying person will be automatically referred to the Spiritual Care team.
Process for monitoring of these will be linked into the nursing accreditation process.

3.12 Bereavement survey

An organisation bereavement survey was undertaken in 2013 by the EOLC Team/Clinical Audit. Action plans developed and taken forward. Some issues included lack of dignity and respect for relatives and poor communication skills, lack of spiritual care support. We have introduced the use of the butterfly across the trust and pursued the delivery of communications skills training for all levels of staff and the spiritual care team automatically offer their support to any every patient who is on an EOLC Individual Plan of Care and Support for the Dying person. The survey was repeated in May 2015. Results now available with an action plan developed. Work has now been undertaken to review the survey and the plan is that this will be available for all bereaved relatives/significant others to receive within the bereavement pack they take on collection of the death certificate. The updated surveys have now been printed and roll out to commence, September 2016.

3.13 Personalised sympathy card

This has now been drafted and ratified via the NMB and the patient experience committee and is to be piloted on wards across sites. This will be sent to all bereaved relatives/significant others expressing sympathy but also giving them the opportunity to meet with any of the clinical team to discuss any issues/concerns they may have. Pilot to commence September 2016.

3.14 Bereavement service developments

A preferred service outline is to be developed jointly between Palliative Care Lead Nurse and General Office/Bereavement Office Manager and the patient experience lead, proposing a model for delivery of bereavement services across the trust. Visits have taken place to other organisations to observe other models.
We have now secured temporary funding for the implementation of property bags, jewellery / hair pouches, personal message card, comfort packs and sympathy cards for relatives across clinical areas. All items have now arrived and the packs are being put together by Newbridge student future finder's volunteers. These have now been disturbed to ward areas for use.
Walk rounds of the bereavement/general offices where relatives/significant others collect death certificates, have taken place and suggestions made in relation to environmental improvements made. Many of these recommendations have now been actioned. This is being monitored via the EOLC steering group.

3.15 uDNACPR

uDNACPR educator now appointed for twelve months. Actions to date include:

- Development of project/action plan to address gaps from previous audit findings
- Undertaken Training Needs Analysis
- Education strategy now drafted to be finalised by September/October
- Lessons learnt taken place from incident reporting and appropriate teaching within clinical area's taking place
- Priority area's for support agreed with EOLC/CCG leads within localities

3.16 KPIs for EOLC

Have now been drafted, to be circulated for wider comments before final ratification via the next EOLC steering group in September 2016

3.17 Hospital Statement of Intent for discharge of EOLC patients from hospital out of hours/over a weekend period.

For the unlikely event that a patient dies following rapid discharge from hospital and before their own GP has had the opportunity to review them, it would help if the hospital medical team could provide a Statement of Intent to avoid unnecessary and distressing police attendance. This will remain valid until 1800 hours on the next working weekday after discharge. As soon as possible, the patient's own GP will review the patient and issue a Statement of Intent that will supersede the one from the hospital.

This is now drafted with guidance notes by Dr Iain Lawrie, currently with the coroners awaiting final agreement prior to coming via the safety committee.

3.18 Prognostic indication guide to identify those patients who are within the EOLC phase

This guide would provide staff with indicators to help identify EOLC patients and then the prompts to consider certain actions e.g. advance care planning, uDNACPR.

The EOLC team are in the process of developing a prognostic indication guidance tool for staff to access on the trust intranet. We are currently working with IT regarding the development of this. This has now been agreed by IT and will be developed and piloted within the next six months on the FGH site.

3.19 Rapid Transfer Pathway

This is fully implemented on the ROH and the NMGH sites. Further roll out has now taken place on the RI & FGH site. From the areas where this is fully embedded into practice of these patients being discharged on this, they are all achieving their preferred place of death, with no further hospital admissions. From the patient stating their preferred place of death is at home and they are in the last days of life, all have achieved discharge within twenty four hours. Patients are discharged in a co-ordinated manner with all anticipatory EOLC drugs.

Conclusion

To conclude this paper provides an update and over view of current Palliative and EOLC initiative's across the trust.

Recommendations

The Committee are asked to:

.
Note, review, consider and endorse the initiatives going forward within the report.

Title: Macmillan Associate Lead Cancer & Palliative Care Nurse
Date of joint Overview and scrutiny Meeting: September 2016