Calderdale and Huddersfield NHS
NHS Foundation Trust

Calderdale and Huddersfield NHS Foundation Trust End of Life Care Strategy 2016- 2017

compassionate care

Contents

Acknowledgements

Acknowledgements

The authors of this strategy would like to thank everyone who contributed to the development of the document.
We also look forward to working closely with all stakeholders in the future to enhance and develop areas to ensure our patients and their families and carers receive a professional compassionate and dignified experience.

End of Life Care definition

A working definition of end of life care has been developed by the GMC (1). For the purpose of this strategy, patients are ‘approaching the end of life’ when they are likely to die within the next 12 months.
This definition includes those where death is expected to be imminent (hours or days).
End of life care involves people with:

a. Advanced, progressive, incurable conditions.
b. General frailty and co-existing conditions that mean they are expected to die within 12 months
c. Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
d. Life-threatening acute conditions caused by sudden catastrophic events.

1. Introduction

Delivering compassionate care to the communities we serve is the vision for Calderdale and Huddersfield NHS Foundation Trust (CHFT). End of life care is one of CHFT's key priorities within the Trust's quality improvement framework.

This strategy sets out CHFT's vision and priorities for 2016- 2017 to meet national expectations and local needs for end of life care (EOLC) for adults under our care. The plan is then to develop an end of life care strategy across Calderdale and Huddersfield health economy, including local commissioning groups, Calderdale and Kirklees Councils, Overgate and Kirkwood Hospices and other voluntary and community GPs. It has been produced following stakeholder engagement and captures local emerging issues.

The importance of high quality EOLC in acute Trusts has for the first time been given weight by its inclusion as one of 8 key areas of inspection for the Care Quality Commission (CQC). CQC reviewed EOLC at CHFT in March 2016 - and has been rated as GOOD across all 5 areas – however a program for future development is still needed to embed end of life care in all settings. This document is directed at all hospital staff and provides information as to how EOLC should be addressed.

The population for Kirklees is around 434,000 and for Calderdale around 209,000, giving a combined population of 643,000. There are approximately 185,000 of the Kirklees population who fall under North Kirklees CCG who direct minimal patient flow to CHFT. So the population served is around 458,000.

For Calderdale and Huddersfield in 2014 around 45% of patients died in Hospital (46.5% Calderdale CCG and 43.5% Greater Huddersfield CCG) (2).
With approximately 50% of people aged over 75 dying in hospital we need to ensure end of life care here is excellent. The elderly population of Kirklees and Calderdale is set to increase: in 2012 there were 102,000 people aged 65 years and over (16% of the population) this is forecast to increase to 169,000 by 2037 (23% population).

This strategy highlights national policy, current service provision (see Appendix 1) and current EOLC local issues. From this we have highlighted 3 priority areas to improve EOLC across CHFT.

- *Priority 1: Identification of people in the last 12 months of life and high quality communication with them to enable excellent care.*
- *Priority 2: Coordinated, timely and equitable access to good care*
- *Priority 3: Good care in the last hours and days of life*

Implementation of the above priority areas will lead to more coordinated care, consistent and equitable access to EOLC services, improved knowledge and understanding in the management of EOLC, and improved patient involvement in care.

2. Vision

The vision is to ensure that people approaching the end of their life and their families are fully supported by high quality services.

End of life care is NOT ONLY everyone's business BUT ALSO everyone's responsibility.

Successful implementation of this strategy relies on ownership at every level from individual staff member, to ward or clinical area, to speciality and division, and to senior management and Trust Board Level.

3. National Policy Context

3.1 National End of Life Care Strategy

In July 2008, the Department of Health published the End of Life Care Strategy for England and Wales, launching a comprehensive programme to transform the care given to people approaching the end of life, their families and their carers. This strategy and accompanying implementation programme is intended to change the culture and experience of dying on 3 different levels: wider societal awareness, service user experience and professional and service delivery infrastructure (3).

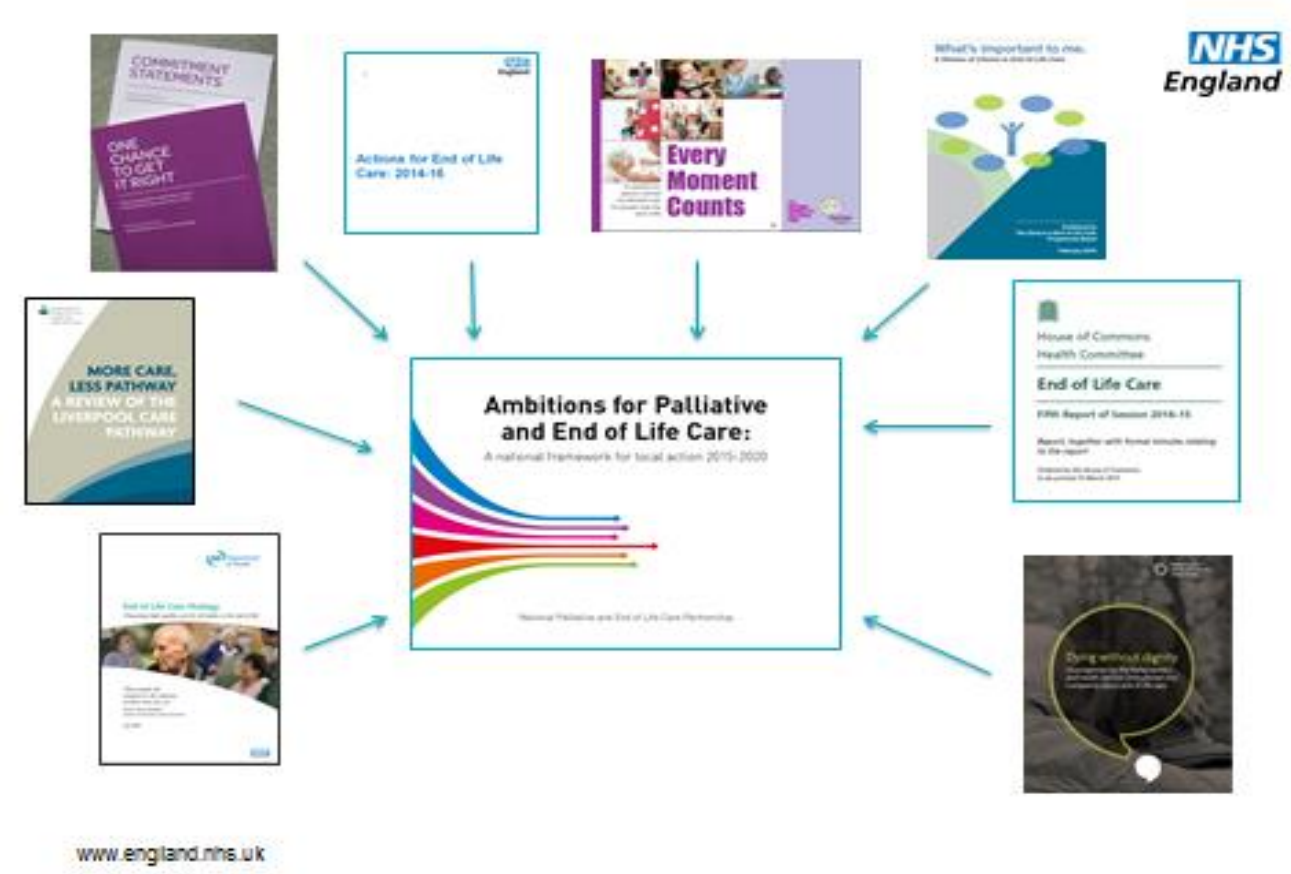
3.2 End of Life Care Tools and guidance documents

The end of life care strategy recommends the use of a range of nationally recognised tools across all organisations. These tools provide practical guidance and support to help health and social care staff implement the EOLC strategy.
Nationally recognised tools and guidance documents include:

- Preferred Priorities of Care (PPC)
- 5 Priorities of care for the dying patient
- Electronic Palliative Care Co-ordination Systems (EPaCCS)
- Gold Standards Framework (GSF) and six steps to success – community tools

Locally, we have implemented an additional tool, the individual care of the dying document (ICODD) to also help with the EOLC strategy implementation.

3.3 Interface with existing strategies and documents



This strategy works alongside the six ambitions for palliative and end of life care (4)

4. Local Context

4.1 Audit

There is a programme of audit currently in place which includes national annual audits and also a local audit that informs the end of life care dashboard.

National audit

- National care of the dying audit for hospital - bi annually
- Annual bereavement questionnaire

Local audit

- Monthly mortality reviews
- Patient reported outcome measures (PROMs) – 3 outcome audit following Specialist Palliative Care intervention and assessment – in house Jan – March 2016

- Patient reported outcome measures (PROMs) – Patients' satisfaction survey - annually
- Individual care of the dying (ICODD) audit
- Monthly Crash calls audited for appropriateness of intervention
- Monthly do not attempt cardio pulmonary resuscitation (DNACPR) audit
- Quarterly review of complaints arising from an admission that ended in death or a death up to 30 days after discharge
- Documentation audits monthly
- Hospital Specialist Palliative Care Team (SPCT) patient experience audit
- Commissioning for quality and innovation (CQUIN) scheme

4.2 National Care of the Dying Audit in hospital (2015)

CHFT was below England average in all five of the clinical indicators and achieved 4 of the 8 organisational indicators (See Appendix 2). The Trust has deteriorated in performance in relation to the time between formal recognition that someone is dying and their eventual death, and evidence of documentation on the holistic assessment of patients and their family's needs. The time between recognising that someone was dying and their actual dying within this Trust was 17 hours compared to a national average of 34 hours (5)

4.3 National Bereavement Audit (2015)

Relatives had confidence and trust in the doctors and nurses caring for their loved ones at the end of life. Although over half of patients experienced pain, restlessness and noisy breathing in the last days of life, it was felt that staff worked hard to relieve these symptoms. However in 20% cases relatives were not alerted to the fact that death was likely soon. For 33% relatives they report there being no discussion about DNACPR decision. Emotional support was rated as poor by 16% and only 18% rated as excellent (30% national figures) 15% of relatives felt spiritual needs were not met at all.(6)

4.4 Individualised Care of the Dying Document (ICODD)

The percentage of patients dying on the ICODD was 45.3% in September 2015 and in June 2016 was down to 36.5%. Agreed a target of all anticipated deaths to be supported by the ICODD

4.5 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

CHFT's target is that 90% of do not attempt cardiopulmonary resuscitation decisions should be discussed with patient, family and/or carer. See box below for results

Date	% discussed with patient/family	
July 2015	88.4	
August 2015	83.3	
September 2015	82.8	
October 2015	92.75	
May 2016	87.64	

From these results it is clear that good quality end of life care is not yet embedded in day to day clinical work in every area.
Pulling together results from the above audits, the Care Quality commission (CQC) inspection report plus national initiatives there are 3 areas of need that have been identified.

5. Development and Improvement Priorities

Common themes have emerged through feedback from audits, reports and stakeholder engagement. These key priorities will form the basis of an implementation plan for work to be carried out across CHFT over the next year with the plan to be developed into a 5 year strategy across the local health economy.

Priority 1 – Identification of people in the last 12 months of life and high quality communication with them to enable excellent care.

- Awareness of and competencies in these skills by both doctors and nurses.
- The use of prognostic indicators (for example the Supportive and Palliative Care Indicator Tool – see Appendix 3) to help identify those in the last year of life.
- High quality handover within and between clinical teams (primary care, secondary care and hospice).

- The use of safety huddles to aid awareness and identification of people in the last year of life.
- Systems in place to facilitate essential conversations with patients and those close to them.

Priority 2-Coordinated, timely and equitable access to good care

- Robust and efficient handover of information and care plans between primary and secondary care.
- Use of Electronic Palliative Care Co-ordination System (EPaCCS). This would require hospital staff to have access to SystmOne, a centrally hosted clinical computer system used by healthcare professional predominantly in the community setting or this may be able to be incorporated within the new Electronic Patient Record (EPR) which the acute Trust is implementing in 2017.
- Robust and unambiguous handover between day staff and night staff particularly in hospitals.
- Supported discharge from hospital to home or nursing home for patients at the end of life with full and widespread use of completed Palliative Care Handover forms, with prescription and provision of anticipatory drugs, and documented plans for future care, including do not attempt cardiopulmonary resuscitation decisions.
- Equitable access to services including those from vulnerable groups such as black or minority ethnic (BME), patients with dementia, learning difficulties, mental health issues, lesbian gay bisexual and transgender(LGBT) patients and the frail elderly.
- Access to syringe drivers in all settings.
- Appropriate and timely referral to Specialist Palliative Care Services and/or advice from Specialist Palliative Care Services.
- Better awareness of issues surrounding the Mental Capacity Act and the role of Best Interests' decisions at the end of life.
- Appropriate and timely access to spiritual care support.

Priority 3: Good care in the last days and hours of life.

This will be underpinned by adherence to the 5 priorities of care for the dying patient which are – recognition, communicate, involve, support and plan and do..

- Awareness of and competencies in recognising dying by doctors and nurses in our organisation.
- Unambiguous, sensitive and compassionate communication about and documentation of their goals of care in the last days of life.
- The use of safety huddles to identify patients who may be starting to die on the wards as well as the number of patients supported by the individualised care of the dying document on any given day.
- Encouragement for the facilitation of proactive family meetings.
- Full use of the individualised care of the dying document for all anticipated deaths and adherence to the advice within this document.

Training and Education is a crucial in all 3 priorities

Training and education in end of life care was recommended to be made mandatory following the National Care of the Dying Audit for Hospitals 2 years ago and this remains an outstanding goal. The 3 crucial areas are enhanced and advanced communication skills, an awareness of and recognition of the 12 months of life, and recognition of the dying phase and the role of the individualised care of the dying document to support patient care.

6.References

1. GMC . Treatment and care towards the end of life: good practice in decision making (2010)

2. Public Health England (2016) – End of Life Care profiles. www.endoflifecare-intelligence.org.uk/end-of-life-care-profiles/

3. Department of health (2008) End of life care strategy

4. Ambitions for Palliative and End of life care:- A national framework for local action 2015-2020. http://endoflifecareambitions.org.uk

5. National care of the dying audit for hospitals (2015) www.rcplondon.ac.uk

6. National Bereavement audit (2015) Voices. www.ons.gov.uk

Appendix 1- Current service provision of Specialist Palliative Care

At CHFT we currently have a 5 day a week multidisciplinary hospital Specialist Palliative Care Team (SPCT) and a Specialist Palliative Care Community team within Calderdale community services. In Huddersfield, community care is provided by Locala and Specialist Palliative Care by Kirkwood Hospice community team.

Both CHFT teams have an advisory role within their settings and patients remain under the care of their own GP in community or under the care of the supervising consultant when in hospital. The team members provide information about diagnosis and treatment and offer specialist advice on the management of difficult symptoms. They also offer emotional, psychological and spiritual support and advice about some benefits and social support. They provide a link between hospital services, community services and both local hospices. The hospital team which covers both sites is based at Huddersfield Royal Infirmary.

The community Specialist Palliative Care Team for Calderdale is based at Overgate Hospice.

Consultants in Palliative Medicine deliver sessions in hospital, community and hospices, with shared contracts with the local hospices.

The Specialist Palliative Care Team at CHFT operates eligibility criteria in common with providers across the Yorkshire and Humber region; these are that patients accessing our services must have active, progressive and potentially life-threatening disease; they must have complex physical symptoms, psychological symptoms or ethical issues, which have not been able to be addressed by the primary caring team; and that they have been assessed by a member of the specialist palliative care team.

The hospital team also provides weekly “in-reach support” with attendance at board rounds and ward rounds in the following disciplines: oncology, haematology, gastroenterology and respiratory medicine. There is also consultant input into the heart failure and respiratory multi-disciplinary team meetings.

Bereavement services are provided by both hospices and the trust has chaplaincy support across the organisation.

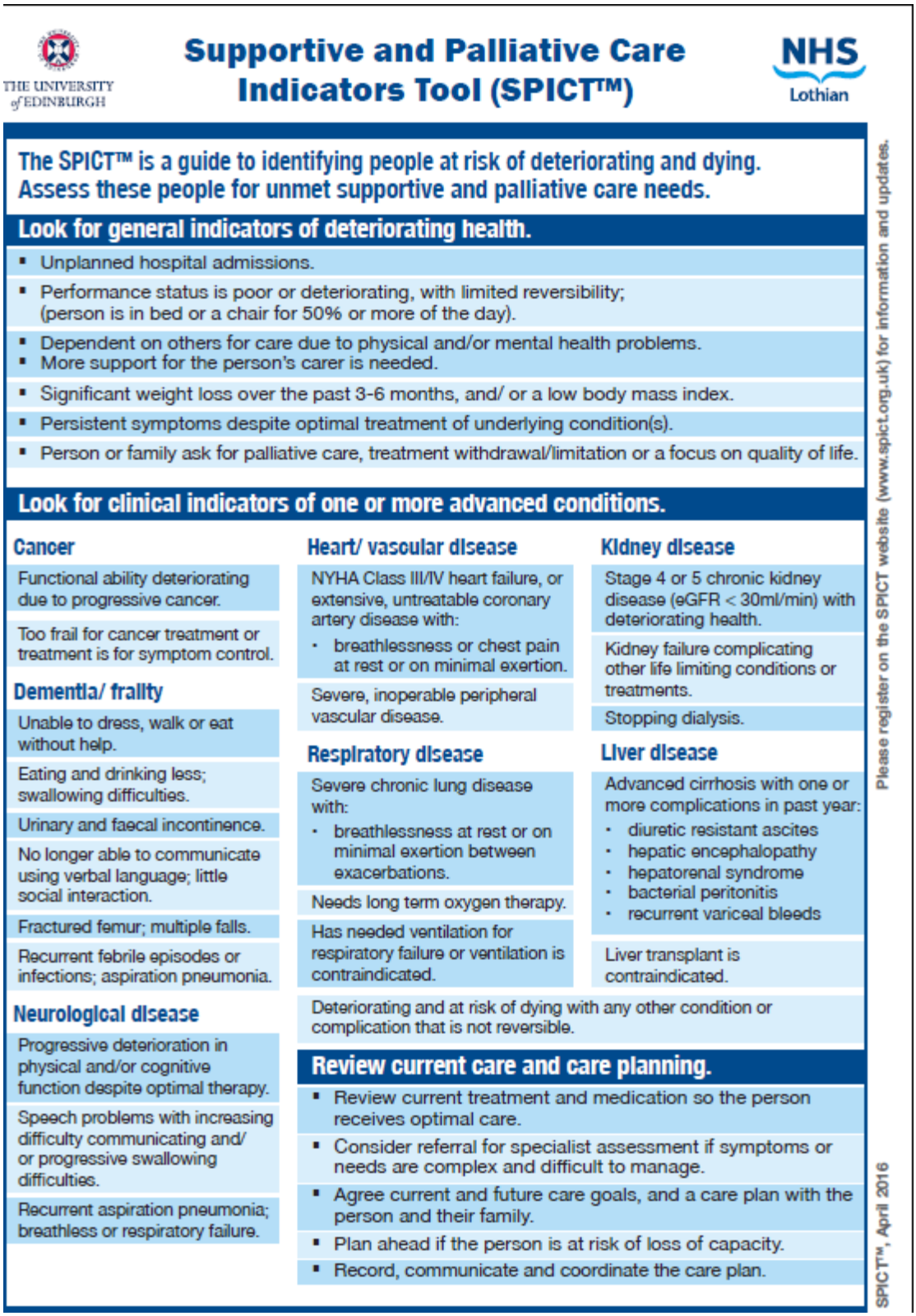
Out of hours’ access to Specialist Palliative Care (SPC) advice is provided by both hospices and by an on call Consultant in Palliative Medicine.

Location	Services provided	Team	Service availability
Acute Trust (CHFT)	Specialist Palliative Care	Dr Kiely – 5 sessions, Dr Oxberry 2 sessions, Dr Ackroyd 6 sessions (across Hospital and Community) and Dr Sheils 2 sessions. Clinical Nurse Specialists, training lead for EOLC, secretarial support, palliative care coordinator and end of life care scoping facilitator.	Monday to Friday 9-5
Calderdale Community Division (CHFT)	Community Specialist Palliative Care	Dr Ackroyd provides 6 sessions for CHFT across the Hospital and Community. Clinical Nurse Specialists. Medical Secretary	Monday to Friday 9-5
Calderdale Community Division (CHFT) Nursing Teams	General palliative and end of life care at home	Full Nursing services, including district nurses, advanced practitioners, community matrons	7 days a week 24/7
Out of hours (OOH) Calderdale	Specialist Palliative Care Out of Hours Nursing Team – I Band 6 Nurse and a Marie Curie Health Care Assistant	Provide Palliative Care support for patients in their own homes out of hours. Working closely with the OOH District Nursing Team	8pm – 5am
Overgate Hospice	Inpatient beds for Specialist palliative care Bereavement Support Services	Dr Sheils is Medical Director and Dr Ackroyd provides 2 sessions per week between Monday to Friday	Overgate have admissions 7 days a week
Kirkwood Hospice	Inpatient beds for Specialist palliative care Bereavement Support Service	Dr Oxberry is Medical Director and Dr Kiely provides 3 sessions per week Monday till Friday.	Kirkwood have admissions 7 days a week
Marie Curie Service	Night HCAs in the patients home.	Marie Curie provide one to one overnight care to end of life patients in the home.	7 nights a week 10pm – 7am

Appendix 2 – National Care of the Dying audit for Hospitals (2015) CHFT results

National achievement against End of Life Care Quality Indicators **CLINICAL AUDIT** **Cases in clinical audit**		**National result** **9302**	**CHFT** **80**
CLINICAL AUDIT INDICATOR		% OF CASES	**% of CHFT CASES**
1	Is there documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days**? %YES**	83%	**71%**
2	Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with a nominated person(s) important to the patient? **%YES**	79%	**68%**
3	Is there documented evidence that the patient was given an opportunity to have Concerns listened to? **%YES or NO BUT**	84%	**75%**
4	Is there documented evidence that the needs of the person(s) important to the patient were asked about? **%YES or NO BUT**	56%	**53%**
5	Is there documented evidence in the last 24 hours of life of a holistic assessment of the patient's needs regarding an individual plan of care? **%YES**	66%	**45%**
ORGANISATIONAL AUDIT		**National result**	**Your site**
Sites in organisational audit		142	**YES**
ORGANISATIONAL AUDIT INDICATOR		% OF SITES	**Your site**
6	Is there a lay member on the Trust board with a responsibility/role for End of Life Care?	49%	**No**
7	Did your Trust seek bereaved relatives' or friends' views during the last two financial years (i.e. from 1st April 2013 to 31st March 2015)?	80%	**Yes**
8A	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Medical staff**	63%	**Yes**
8B	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Nursing (registered) staff**	71%	**Yes**
8C	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Nursing(non-registered) staff**	62%	**Yes**
8D	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Allied Health professional staff**	49%	**No**
9	Access to specialist palliative care for at least 9-5 Mon-Sun	37%	**No**
10	Does your trust have 1 or more End of Life Care Facilitators as of 1st May 2015?	59%	**No**

Appendix 3 – Supportive and Palliative Care Indicators Tool (SPICT)



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Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assess these people for unmet supportive and palliative care needs.

Look for general indicators of deteriorating health.

- Unplanned hospital admissions.
- Performance status is poor or deteriorating, with limited reversibility; (person is in bed or a chair for 50% or more of the day).
- Dependent on others for care due to physical and/or mental health problems.
- More support for the person's carer is needed.
- Significant weight loss over the past 3-6 months, and/ or a low body mass index.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- Person or family ask for palliative care, treatment withdrawal/limitation or a focus on quality of life.

Look for clinical indicators of one or more advanced conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Deteriorating and at risk of dying with any other condition or complication that is not reversible.

Review current care and care planning.

- Review current treatment and medication so the person receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the person and their family.
- Plan ahead if the person is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2016