

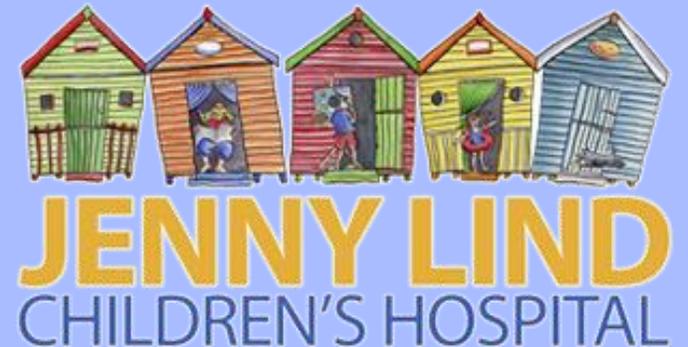
Children with non-oncological life-limiting conditions deserve the same high-quality palliative care as children with incurable cancer

*Results of a retrospective case-notes audit*

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# Aims of the audit

- To determine if all children with LLCs have their palliative care needs assessed, planned and delivered - as per standards set out by Together for Short Lives (TfSL).
- To aid the development of a local guideline and framework (care pathway) to ensure the above happens.

# TfSL Core Care pathway for Children with Life-limiting and Life-threatening Conditions

## Stage 1 : Diagnosis and/ or recognition

- Sharing significant news – diagnosis and prognosis
- Liaison with and/ or transferring to community services

## Stage 2 : Ongoing care

- Multidisciplinary assessment of needs
- Child and family care plan/s

## Stage 3 : End of life

- End of Life plan
- Bereavement support

# Methods

- Inclusion Criteria
  - Children who had died as a direct result of a condition/s that is clearly life-limiting, 2011-2015
- Exclusion criteria
  - Sudden/ unexpected deaths even in children with a LLC diagnosis
  - Children whose care was mainly led by another hospital
  - Deaths on the neonatal unit, or within a month of diagnosis of LLC
- Data collection
  - Case notes, electronic databases, M&M minutes

# Distribution of main diagnoses

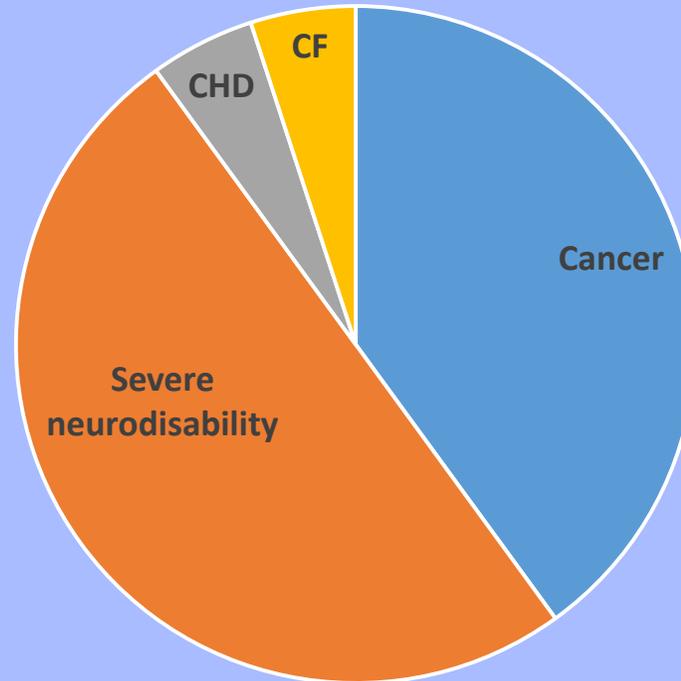
Total: 20

Oncology: 8

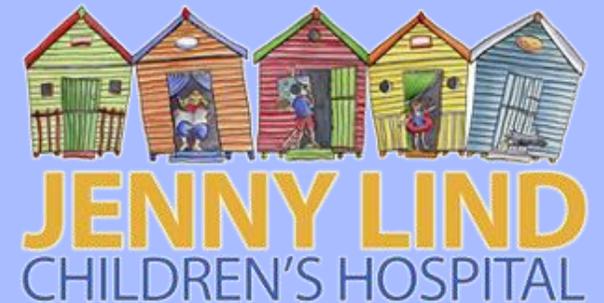
Severe neurodisability: 10

Complex congenital heart  
disease: 1

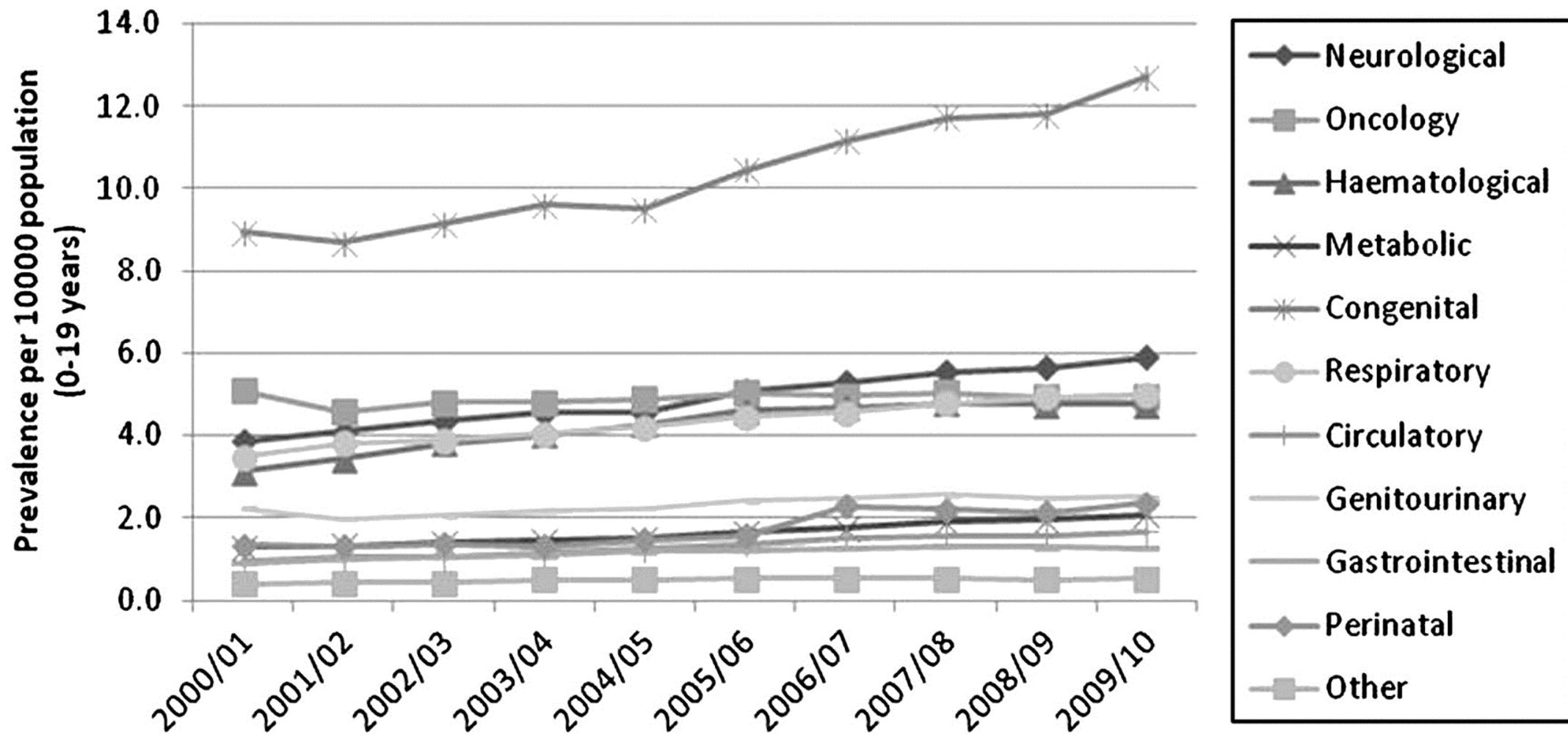
Cystic Fibrosis: 1



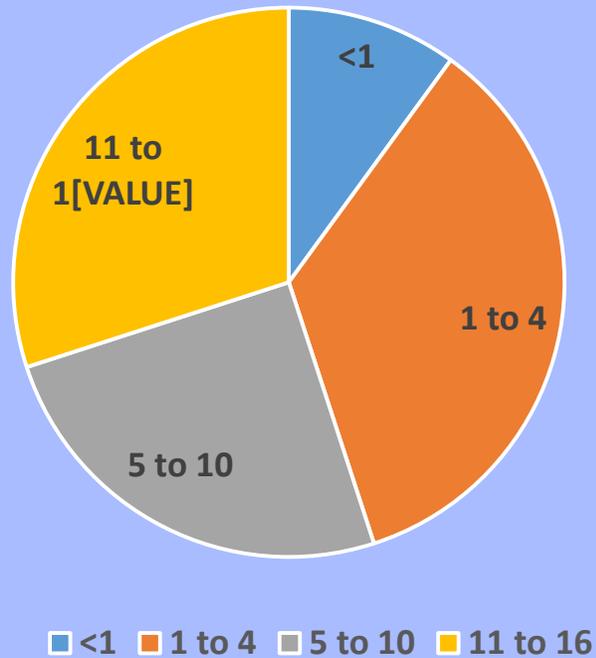
■ oncology ■ severe ND ■ CCHD ■ CF



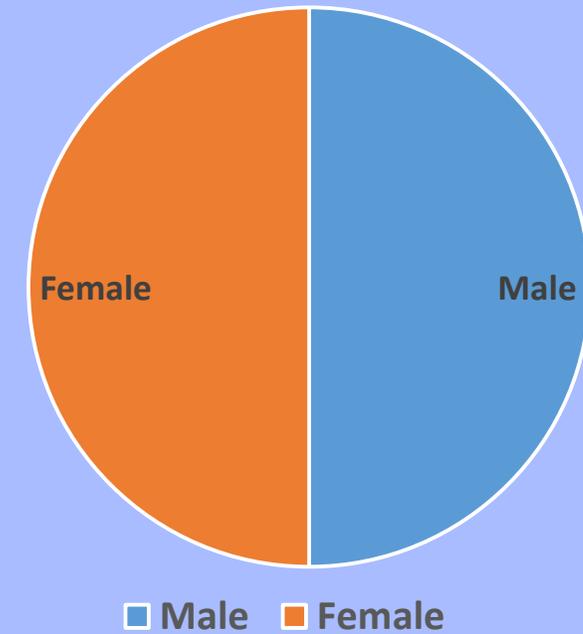
# Prevalence of Life-Limiting Conditions in children in England by Major Diagnostic Group, 2000-2010



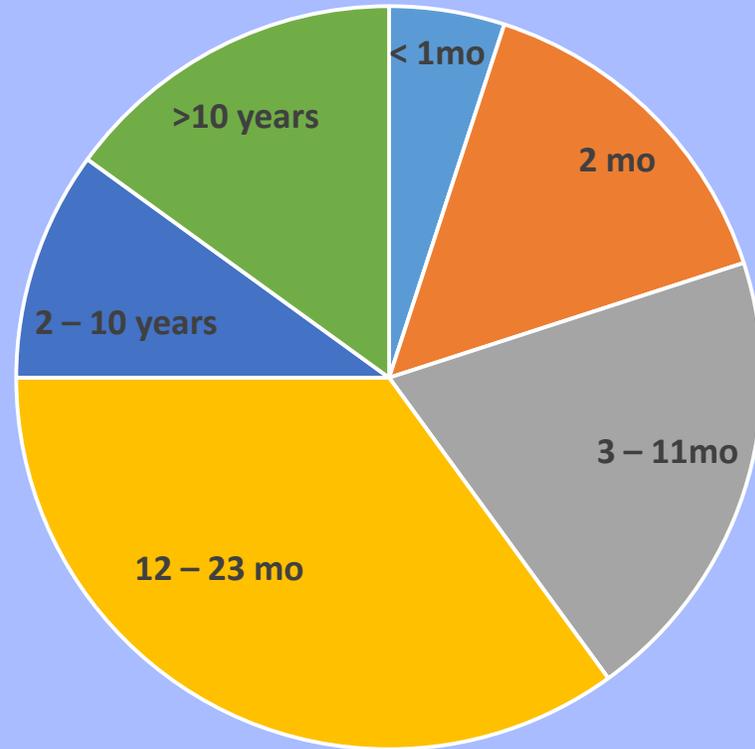
# Age at death



# Sex



# Time from confirmation of LLC to death



■ 1 mo ■ 2 mo ■ 3 to 11 mo ■ 12-23 mo ■ 2 to 10 years ■ > 10 years

# Audit Standards and results

1. There should be an honest discussion with the parent/s of all children with life-limiting conditions when such is identified, in an appropriate setting, and this should be documented in the hospital notes: 100%

**Documented in 19/20: 95%**

But...discussions about the life-limiting nature hardly documented

Oncology: 'no more curative options'

# Audit standards and results

2. An initial MDT meeting should be held to assess needs and plan delivery of care: 100%

**Result: 17/20: 85% (Onc: 100%, Non-onc: 75%)**

3. The MDT should identify a key worker and a lead clinician: 100%

Result: Both clearly identified in 9/ 20: **45%**

**(Onc: 87.5%, non-onc: 20%, p = 0.01 )**

- One or the other in 9
- Neither in 2

# Audit standards and results

4. The child's palliative care needs (including current and anticipated symptoms) should be assessed by the MDT and documented

**Result: 12/20 60%**

**(Onc: 100%, non-onc: 33.3%, p = 0.015 )**

5. Symptom management plans (including roles of clinicians and lines of communication) made

**Result: 13/20 66.7%**

**(onc: 100%, non-onc: 41.7%, p = 0.0225)**



# Audit Standards and results

6. Family structure and psychosocial and cultural needs should be assessed and documented

**Result: 15/20 75%**

**(Onc: 100%, non-onc: 58.3%)**

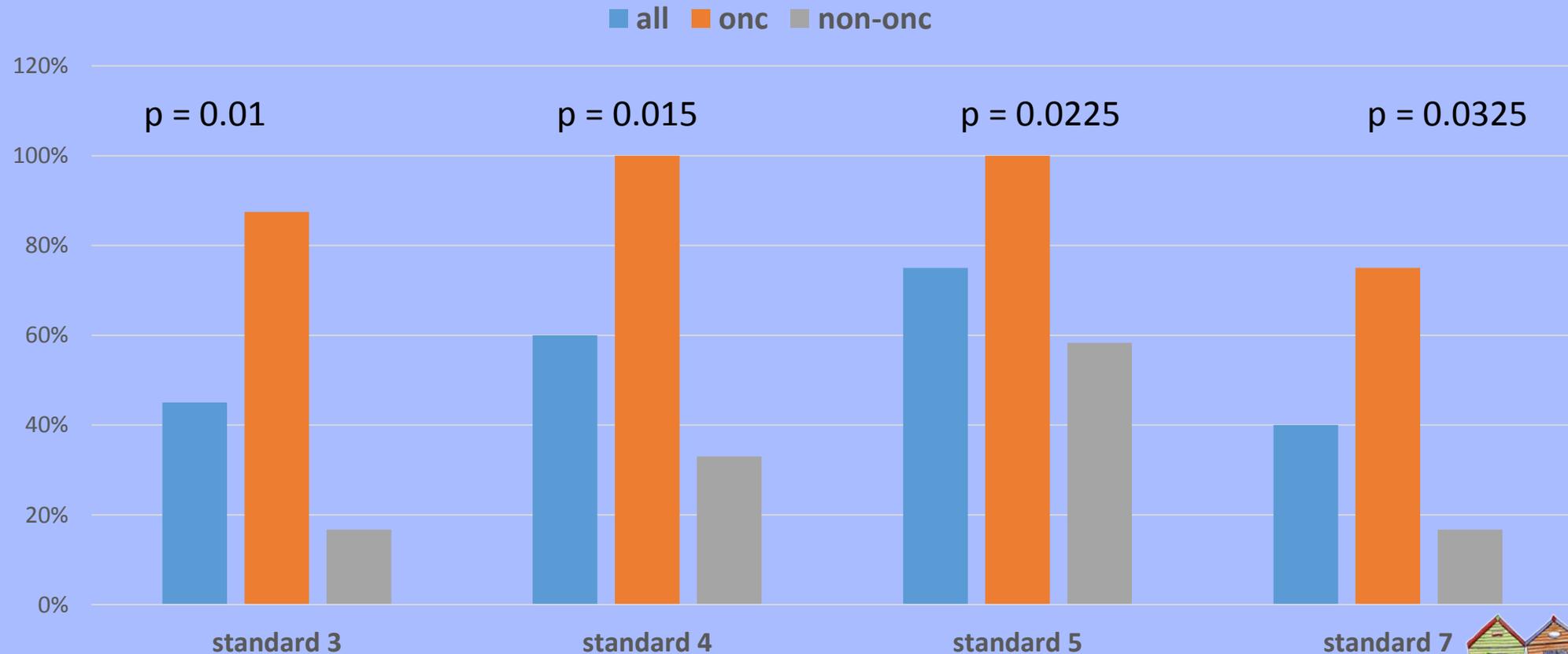
# Audit Standards and results

## 7. End of life care plans should be discussed and documented:

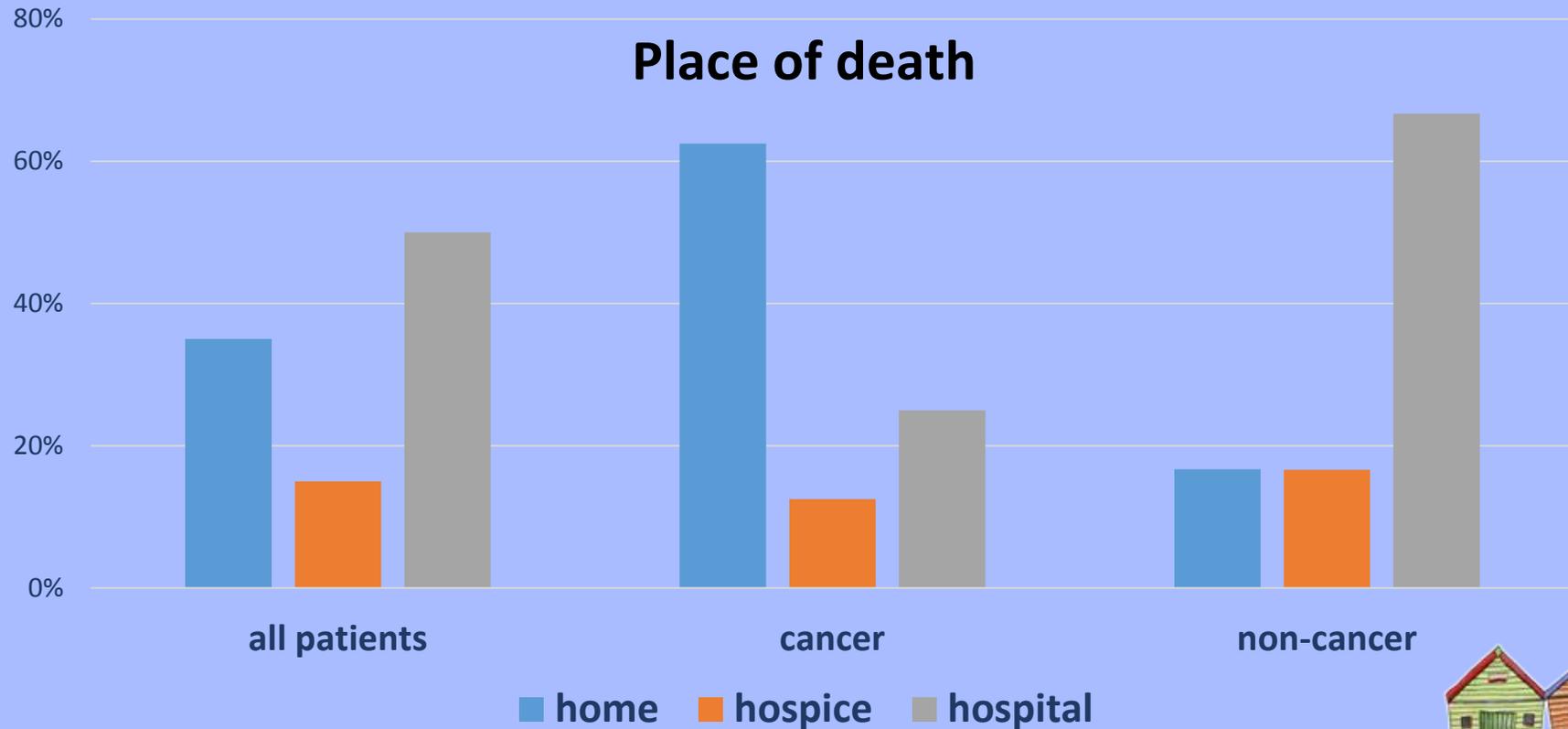
- a) **DNACPR: 13/20 66.7%** (including 3 that did not engage)  
(Onc: 100%, non-onc: 41.7%)
- b) **Place of EoL care/ death: 11/20 55%**  
(Onc: 100%, non-onc: 25%)
- c) **Other wishes and desires: 9/20 45%**  
(Onc: 75%, non-onc: 25%)
- d) **All 3: 8/20 40%**  
(Onc: 75%, non-onc: 16.7%,  $p = 0.0325$  )



# Comparison cancer vs non-cancer



# Other observations (1)



# Other observations (2)

- Intensive care: 4 (0 oncology)
  - 1 for 3 weeks
  - 1 for 32 days
- Resuscitation: 4 (0 oncology)
  - 2 prolonged full CPR (one had SUDIC protocol)
  - 2 partial (short of cardiac massage and drugs)

# Summary of findings

- Poor documentation – especially of communication of prognosis and lead professional/ key worker.
- MDT assessment and planning incl. end-of-life care planning grossly inadequate – especially in non-oncological LLC
- Clear disparities between oncological and non-oncological LLC

# Oncology versus non-oncology

- Often clear demarcation between ‘potentially curable’ and ‘non-curable’
- ‘Futility’ more acceptable a concept given the social and cultural connotations of the ‘C’ word?
- Clear regional palliative care pathway for children with oncological diagnoses
- Limited research suggests that this is reflected in families’ perception of services (Price et al, 2012)

# Recommendations/actions

- Care pathway and guideline for MDT management of children with LLCs - written
- Database of CYP with life-limiting conditions
- LLC forum and care coordinator
- Named paediatrician/s for palliative care
- Rolling (annual/biannual) MDTs for all children with LLCs
- Education programme : several completed already
- County-wide clinicians' group
- Commissioners and acute Trust beginning to engage

# References

- MCNAMARA, K. 2013. Standards Framework for Children's Palliative Care, 2/e. Bristol: *Together for Short Lives*. A framework for the development of Integrated Multi-Agency Care Pathways for children with life-threatening and life-limiting conditions, *ACT*, 2004
- CRAIG, F., et al. 2007. IMPaCCT: Standards for paediatric palliative care in Europe. *European Journal of Palliative Care*, 14(3), 109-114.
- Rushton, C.H., 2005. A Framework for Integrated Pediatric Palliative Care – Being with Dying. *Journal of Pediatric Nursing*, 20(5), 311-325
- Better Care: Better Lives. 2008. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions. *Department of Health*.
- NHS STANDARD CONTRACT FOR PAEDIATRIC MEDICINE: PALLIATIVE CARE 2013/14. *NHS Commissioning Board (now NHS England)*
- Child & Young Person's Advance Care Plan Policy - April 2011 *West Midlands Paediatric Palliative Care Network*
- PRICE, J. et al., 2012. Comparing the needs of families of children dying from malignant and non-malignant disease: an in-depth qualitative study. *BMJ Supportive & Palliative Care*, 2, 127-132.
- HAIN, R., DEVINS, M., HASTINGS, R. & NOYES, J. 2013. Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. *BMC Palliat Care*, 12, 43.
- FRASER, L. K., et al., 2012. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*, 129, e923-9.