

# Experience from a home-based palliative care service in Malaysia

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# Background: Palliative care at home

## Hospis Malaysia (1991)

- ★ Charitable organisation, NGO
- ★ Largest home-based service provider - greater Kuala Lumpur
- ★ All children with palliative care needs
- ★ Involve in training and education (1997)

# Background: Palliative care in hospitals

- ★ Tertiary centres: paediatricians for their own patients
- ★ General hospitals: when patient's return from tertiary centres



# Background

- ★ Tertiary centres: paediatricians for their own patients
- ★ General hospitals: when patient's return from tertiary centres



- ★ 2012 National Paediatric Palliative Initiative
- ★ Increased awareness amongst paediatricians
- ★ Paediatric Palliative Care Workshop at Hospital  
Malaysia

# Objective

Describe the home paediatric palliative care service provided at Hospis Malaysia

# Methods

- ★ Retrospective study
- ★ 4 years: 1<sup>st</sup> January 2014 to 31st December 2017
- ★ Children  $\leq$  21 years
- ★ Data collected from electronic data system + folders
  - demographics and diagnosis
  - service received by patients and families



# Results: Patient cohort (2014 - 2017)

**191 patients**

**15 (from 2013)**

**176 (2014-2017)**

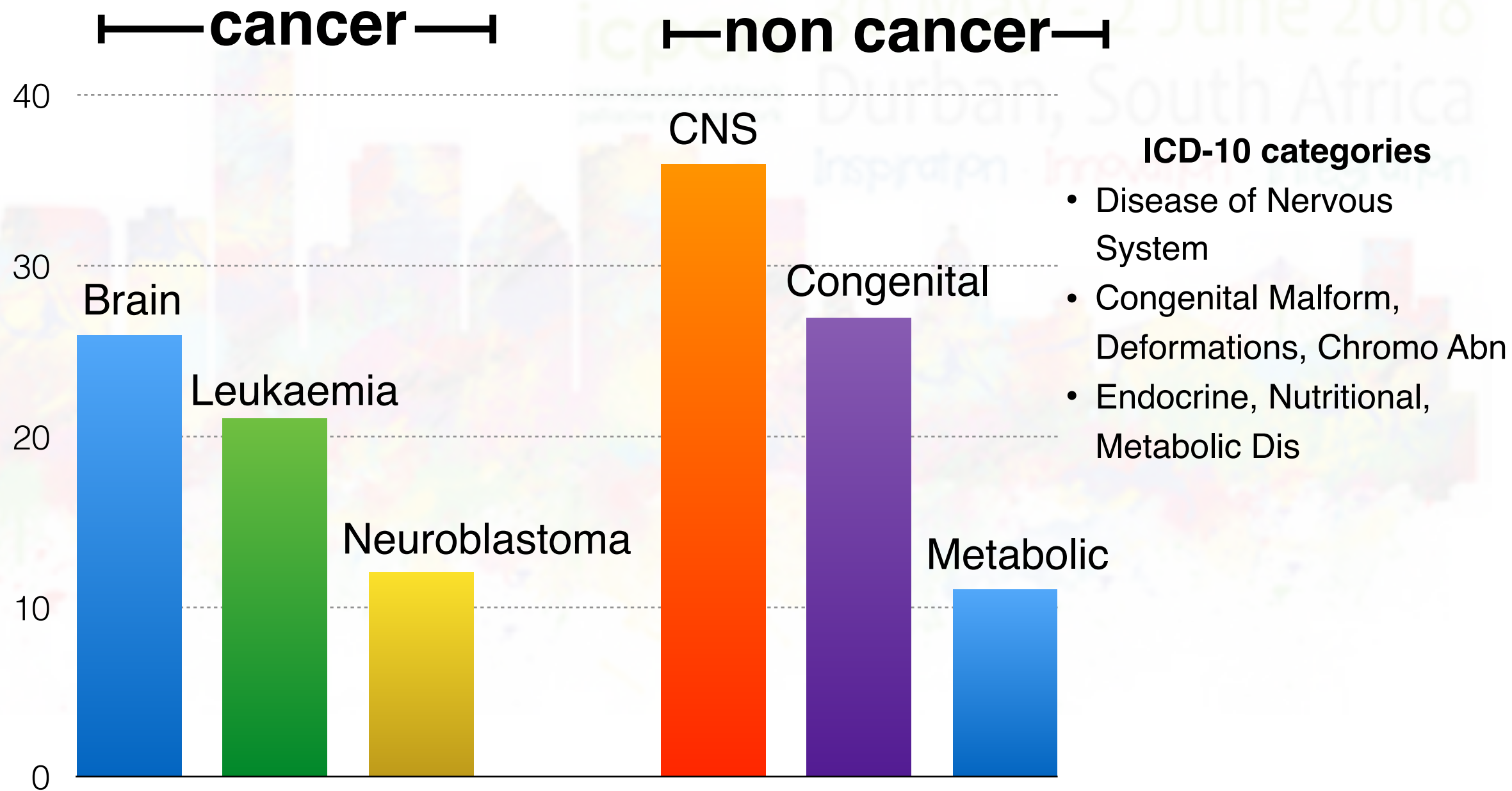
# Results:

- ★ Gender: 85 females (44.5%)
- ★ Age: median 86 mths (range: 3 days - 19yrs 10mths)
- ★ Referrer: Government hospitals 91.6% , private 8.4%
- ★ Contact by next working day: 73.2% families

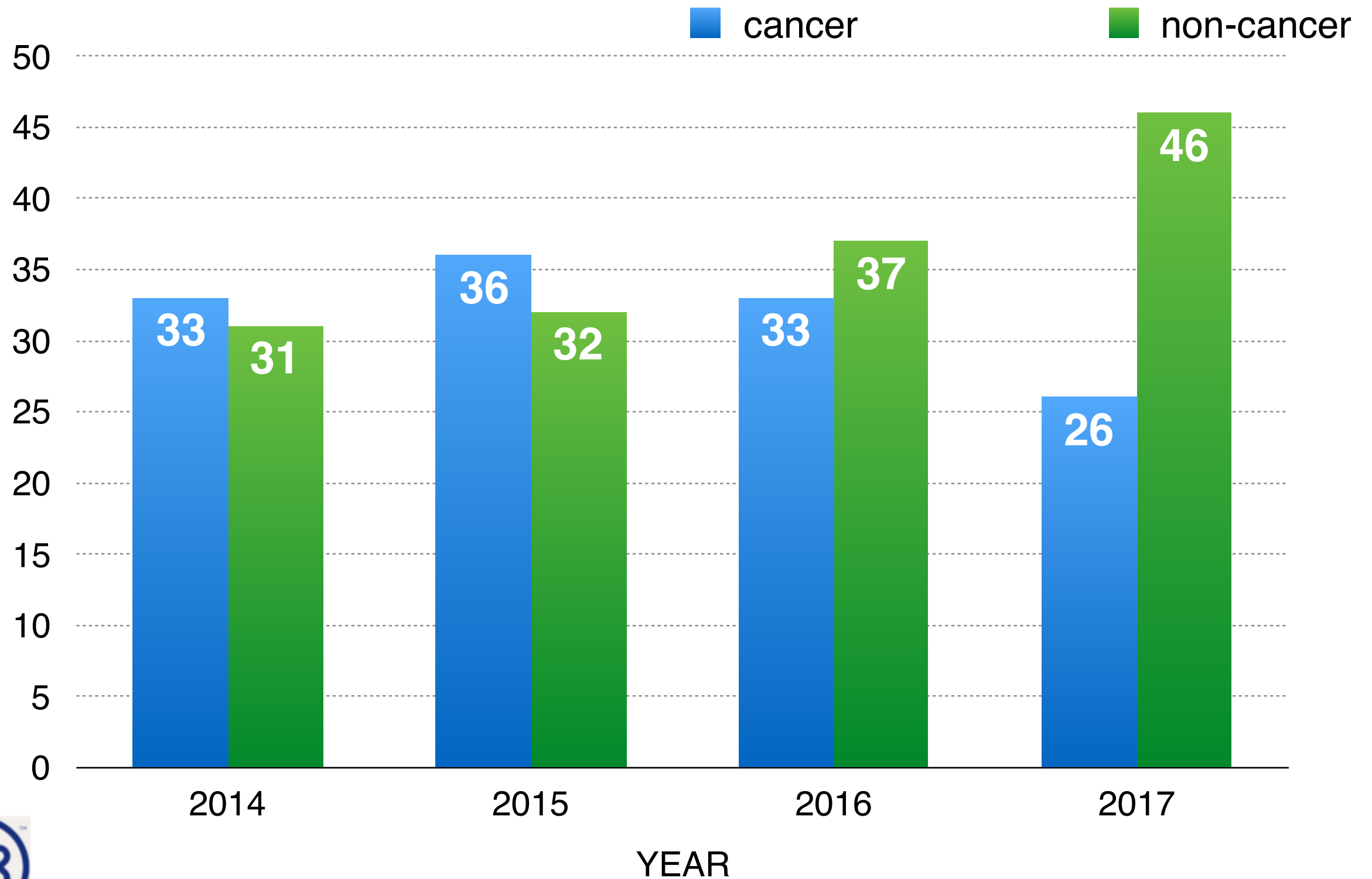


# Results: Diagnoses

★ Malignancy: 98 (51.3%)



# Results: Diagnoses



# Results: Patient cohort

**191 patients**

**149 (home visits)**

**42 excluded**

- 1 - prior to 2014, incomplete data**
- 1 - still in hospital**
- 15 - discharged**
  - 5: prolonged admission**
  - 4: not keen for service**
  - 3: uncontactable**
  - 3: out of service coverage**
- 25 - died before home visit**
  - 8: at home, 17: hospital**



# Results: N=149

## Symptoms

- ★ 71.1% had at least one symptom at initial visit

Pain 39.6%

Constipation 18.9%



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Pain Integration

# Results:

## **Medical devices: 88 (59%) of patients**

(BiPAP, Tracheostomy, Nephrostomy, Chemoport, VP shunt, urinary catheter, nasogastric tube, orogastric tube, gastrostomy)

★ Most common was for feeding (78.4%)

nasogastric tube 78.3%

orogastric tube 10.1%

gastrostomy 11.6%

# Results: Patient Contact

## ★ Home visits:

median: visit every 15 days (range: 1.4days - 87days)

## ★ Phone calls & home visits:

median: contact every 3.7 days

(range: 3.8 contact in 1 day -1 contact in 14days)



# Results: Out-of-hours service

- ★ Phone call: 38.4% of patients
- ★ Emergency home visits: 27.4% of patients
- ★ Cancer vs non cancer,  $p=0.220$

# Results: Patient cohort

**191 patients**



**149 (home visits)**



**97 (65%) died**  
**32 (21%) alive**  
**20 (13%) discharged**

# Results: Referral to death, N=97

★ Median time: 94 days (2 - 3242 days)

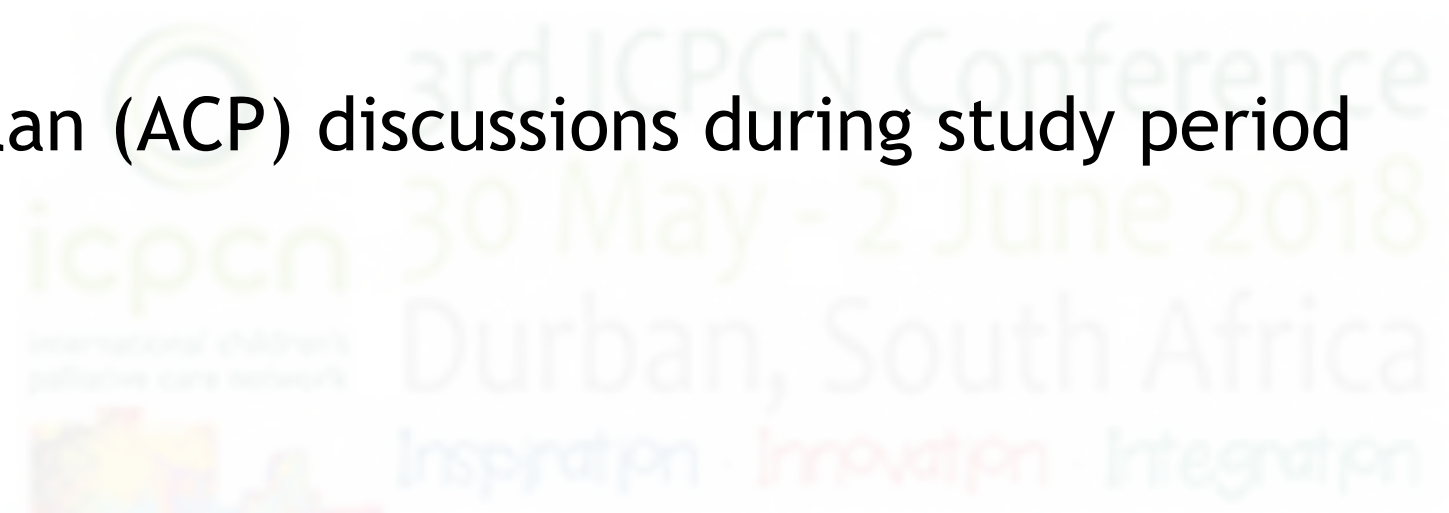
★ cancer: 60 days (2 - 1281 days)

★ non-cancer: 217 days (5 - 3242 days) ( $p=0.001$ )



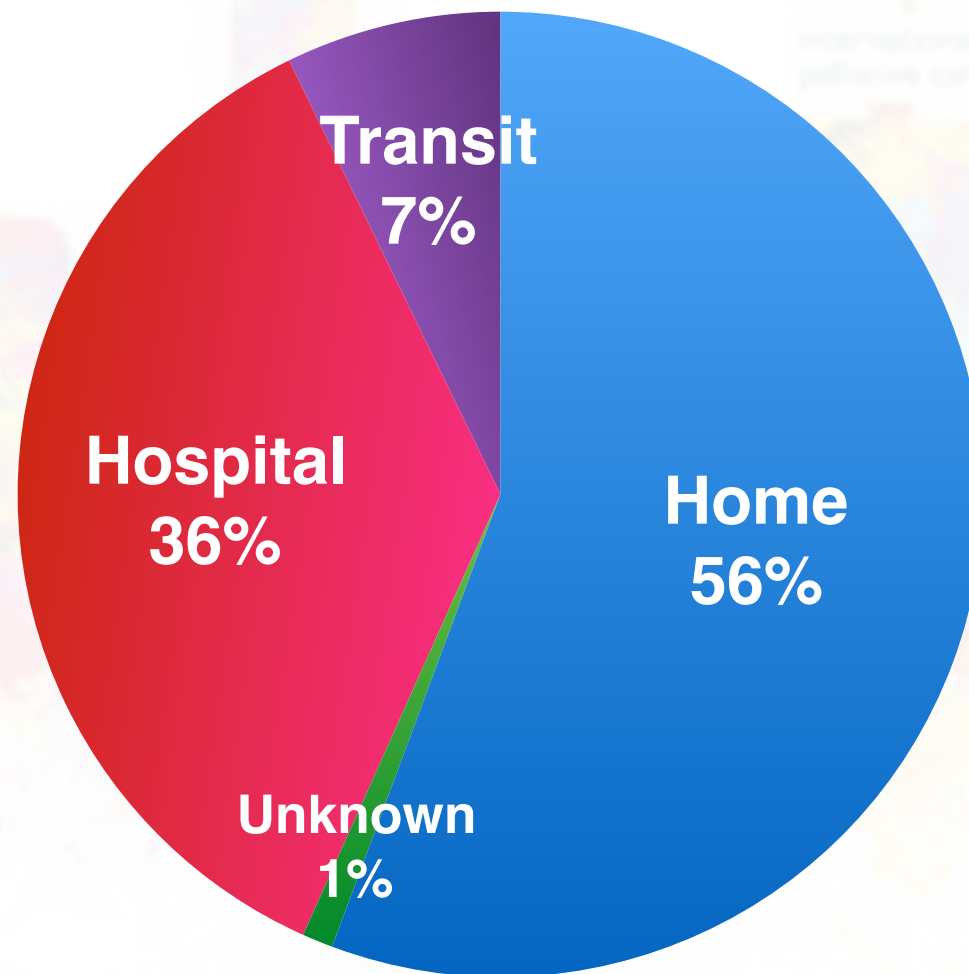
# Results: N=97

- ★ 64.9% had advanced care plan (ACP) discussions during study period



# Results: Location of death

**72.2% wished for home death, died at home**



# Results: Bereavement

- ★ 91.8% had follow-up (call +/- visit)
- ★ no complicated grief



# Discussion

- ★ Increased awareness of palliative care needs of children with non-cancer diagnoses
- ★ Referrals are at children's terminal admission (13% of all referrals)
- ★ Children's symptoms are not well managed
- ★ Home care service
  - ★ support and care for medical devices (NGT, PEG)
  - ★ out of hours needs not diagnoses dependent
  - ★ staff needs training to carry out ACP conversations
  - ★ better support home deaths

# Limitations

- ★ Restrospective audit
- ★ Documentation provider dependent



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# Conclusion and future studies

- ★ Training and education for general palliative care providers
- ★ Parents are expected to provide medical care at home
- ★ Prospective studies
  - ★ patients and parents experience and satisfaction of the service
  - ★ effectiveness of symptom treatment