

# Retrospective Study of the Location of Death of Children referred to the Specialist Palliative Care Team over a two year period.

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## Introduction

The Specialist Paediatric Palliative Care Team (SPPCT) in Our Lady's Children Hospital Crumlin (OLCHC), Dublin is the only specialist team in the Republic of Ireland.

The SPPCT plays an important role in the care of Children and their families from time of referral through to bereavement, regardless of where the Child dies; home, hospital, hospice or elsewhere.

With significant advances in treatment of previously fatal conditions and with better supportive care, more Children who receive palliative care in the hospital setting.

The SPPCT undertook a retrospective audit of all deaths of Children referred over a 2 year period to look at place of end of life care. Similar data was recorded in A Palliative Care Needs Assessment for Children (2005) <sup>1</sup> which reported many children who died with cancer were able to die in their own homes. Their data figures indicated at that time in Ireland the majority of children who died of life-limiting illnesses other than cancer did not die in their own home.

## Aim of the project

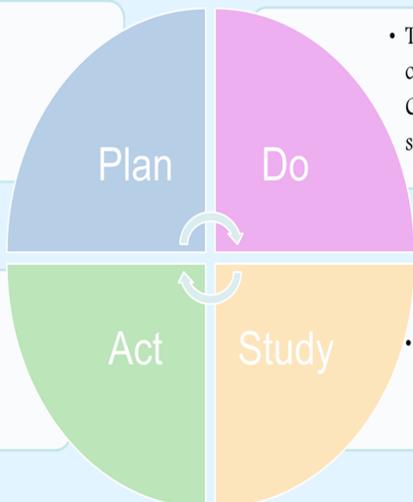
- To audit the location of death of all Children referred to the SPPCT service over a 2 year period.
- To record the ACT Category of Children who died. The ACT Categories define 4 broad groups of life-threatening and life-limiting conditions which may require Children's palliative care provision<sup>2</sup>

## Method

- Charts and electronic database were retrospectively reviewed by the Clinical Nurse Specialist (CNSp).
- Inclusion criteria : all Children who died under the care of the SPPCT from 01/01/2015 to 31/12/2016.
- Confidentiality was maintained at all times.
- Data collected included (1) location of death and (2) ACT Category of the child's illness.
- Data analysis conducted by SPPCT.

## PDSA

- SPPCT to quantify the number of deaths within a hospital setting versus community setting



- To audit the location and ACT category of deaths of all Children referred to the SPPCT service over a 2 year period

- Disseminate findings to key stakeholders.

- Conduct analysis of findings and trends 2015 versus 2016.

## Results

In total the service recorded 136 deaths over the 2 year period. The information provides insight as to whether the location of death is influenced by the ACT Category attributed to the Child's diagnosis. Results show 43% of Children referred died in hospital, 53% at home, the remainder in hospice (3%) and other (<1%).

The majority of ACT Category 1 deaths recorded were of Children with cancer. Over this period children with Category 1 diagnosis accounted for 47 of the deaths, of which 67% died at home.

## Results

Findings of the audit indicated the total number of deaths over 2 years equaled 136 Children.

Fig.1. Demonstrates the number of deaths per location, revealing 72 Children died at home with the additional support of Specialist Adult Palliative Care Teams (SAPCT).

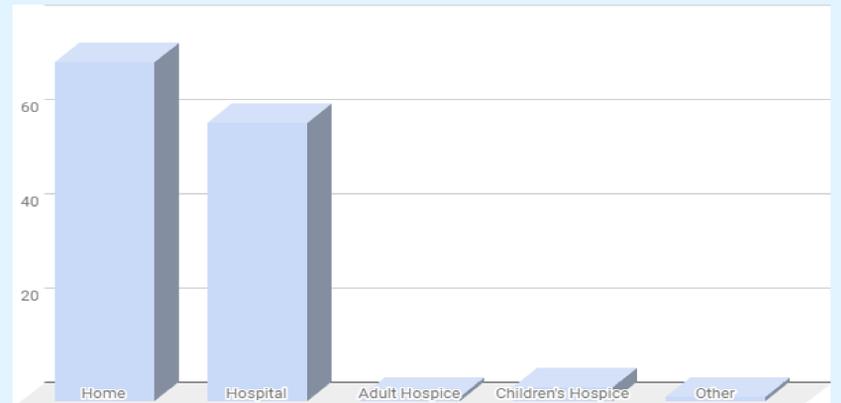
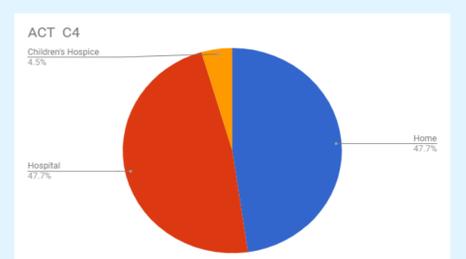
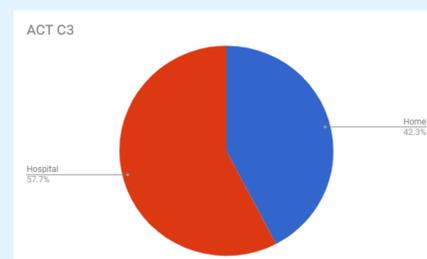
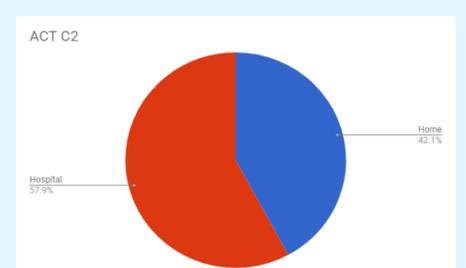
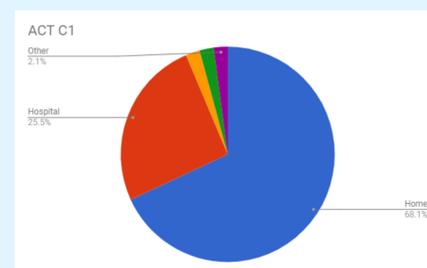


Fig.2 – Each Act Category and location of death. ACT Category 1 clearly records the highest number of home deaths, ACT 2 & 3 show a significantly lower number of deaths at home. Children with an ACT Category 4 diagnosis denotes the 3 deaths that occurred in a Children's hospice.



## Conclusion

It is possible that modern advances in treatment result in more Children with cancer dying in hospital. This has implications for resourcing hospital based SPPCTs.

An increase in deaths at home for Children with non cancer diagnoses is welcome and possibly reflects many factors; such as the establishment of the Clinical Nurse Coordinator for Children with Life limiting Conditions, and better coordination with community teams.

The establishment of the SPPCT in OLCHC plays a pivotal role in supporting the multi-disciplinary teams caring for children in the community.

## References

- Department of Health and Children and The Irish Hospice Foundation – A Palliative Care Needs Assessment for Children 2005
- ACT: A Guide to the Development of Children's Palliative Care Services. 2009, Bristol, UK : Together for Short Lives.

Acknowledgment: Suzanne Dunne CNM3 Quality, Licensing & Standards Department, OLCHC.