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Learning after a child's death


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Figure 6 Patient and family goals



Background

The sub speciality of paediatric palliative care is continuing to gain recognition in paediatrics and within the specialist palliative care field. The Paediatric Palliative Care Service (PPCS) is based at the Royal Children's Hospital (RCH), Brisbane. The PPCS is a consultative service for the state of Queensland, northern New South Wales and the Torres Strait. This service has evolved from an oncology based service to one that receives referrals from both the oncology and non-oncology groups. The approximate number of referrals per year is 100 with 50 deaths per year.

The PPCS exists to ensure quality services are provided to children and young people who are living with a life limiting condition, and who are expected to die during childhood as a direct result of that condition. The primary aim of the service is the provision of competent and compassionate care at the end of life, for all children. To ensure that this aim is being met and the service continues to develop, quality measures have been integrated into the team's everyday practices. One of these is the completion of a death review process.

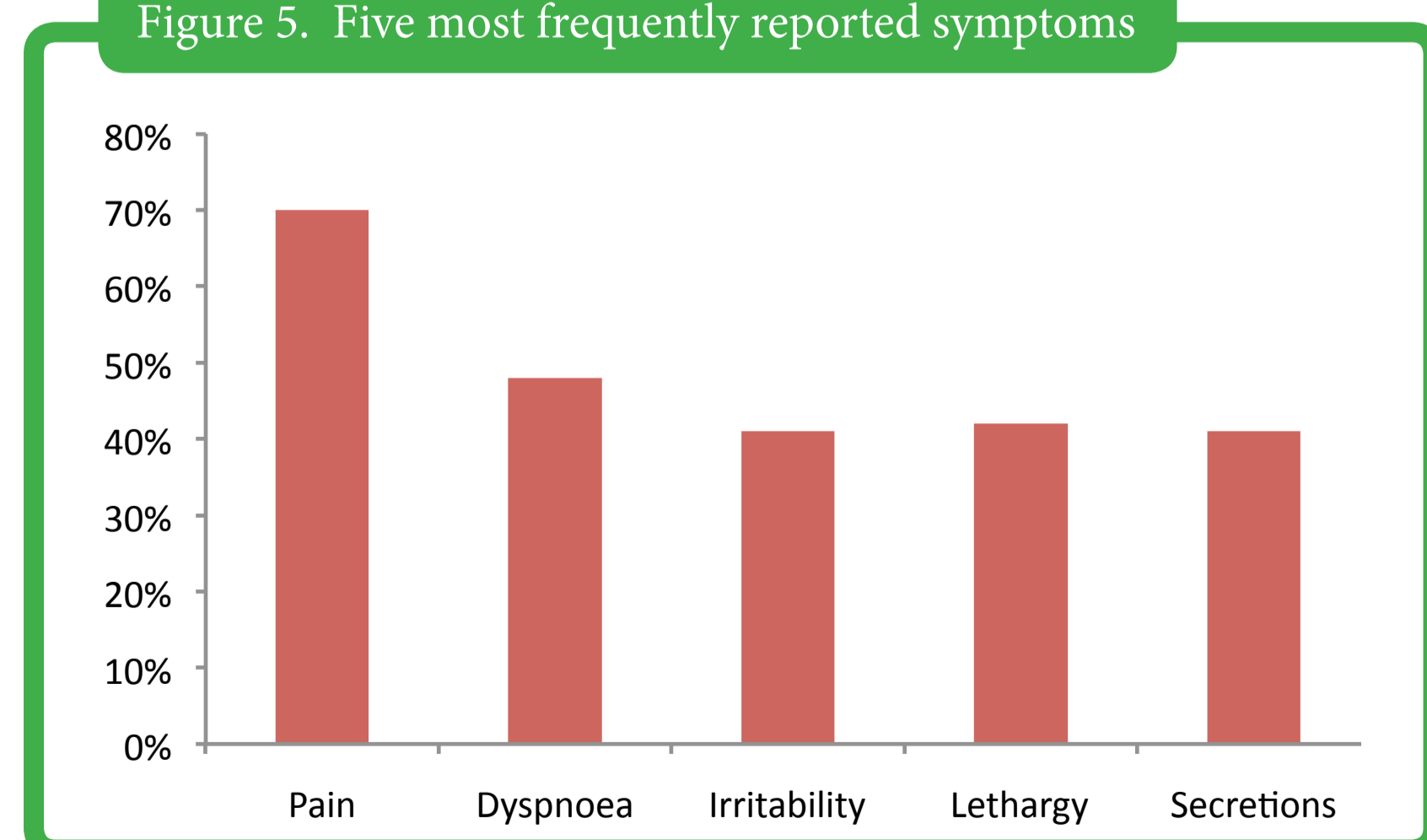
The death review process

The purpose of the review process is to examine the individual cases with reflection of the expected standards of care that are paediatric specific. This includes 22 clinical indicators developed by the Australian and New Zealand Paediatric Palliative Care Reference group. They are also in keeping with the *Standards for providing quality palliative care for all Australians (4th Edition)*, the family's goals and excellent clinical care. The PPCS team has a meeting allocated to the review process on a weekly rotation. Separate meetings are allocated for the oncology and non oncology groups. The patients to be discussed are highlighted ahead of the meeting to ensure the key people involved are able to attend, some by teleconference if necessary. In the interest of time, the electronic death review form is pre populated by the key PPCS team member familiar with the case.

During the multi disciplinary team discussion, the form is worked through and relevant issues discussed, noted and action plan allocated. A bereavement plan is also created and documented at this time. On completion, the form is filed into patients medical notes. To conclude the discussion of that case, a river rock is inscribed with the child's name and placed in a tall glass vase. This ritual provides an opportunity for staff reflection, personal expression and team acknowledgment of the child's loss.

Key areas addressed include the recommended data sets and other information sought by the service: demographics, place of death, age at initial consult and death, ethnicity, diagnostic group, length of engagement with the PPCS, involvement with the nurse practitioner of the service, use of the toll free 1800 number, symptoms during the palliative and end of life phase, presence of a family member with the patient at time of death, community services offered, preferences for end of life discussed, and whether the family had adequate access to the right location at the right time at the time of death. Also collected are the goals expressed by the families and children themselves, any lessons learnt by the team during the care of that particular case and any quality activities that resulted from those learnings.

Figure 5. Five most frequently reported symptoms



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The results

Over a 30 month period (January 2010 end June 2013) the reviews of 171 patients were analysed Figure 1 presents the diagnostic categories of referrals and the age at death is presented in Figure 2. The location of residence of families is presented in Figure 3, and the location of death in Figure 4. The five most frequently experienced symptoms are presented in Figure 5.

Qualitative data that was collected regarding patient and family goals, lessons learnt and things that 'went well' were analysed using NVivo. Themes and word frequencies were examined and are presented in word clouds in Figures 6, 7 and 8. Larger texts of words are those that were found more frequently in the data.

This study highlighted the heterogeneous group of patients and diverse needs of families who are referred to paediatric palliative care. Many families wish to care for their child at home and this was achieved 58% of the time. For others whose child may have died in the hospital or hospice, most were offered the option of home care. Community services and respite were offered to those who needed it and were managed at home for a significant period of time prior to death.

The recognition of school, siblings and the creation of positive memories was evident in the family goals listed. For those whose goals were recorded as 'not met', it was usually due to a sudden change in the child's condition. The common themes around 'lessons learnt' by the team included; the need to ensure families were supported with appropriate access, management of multiple services, good communication and an understanding of the role of the PPCS. Things that were listed as 'done well' included excellent team work to ensure the management of a child's death was aligned with family goals, along side good 24 hour support for the family and involved health professionals.

Follow up

The death review process conducted by the PPCS will continue to evolve to meet the ever changing needs of the standards and evidence. As the new Queensland Children's Hospital opens in late 2014, more electronic forms and systems will develop. The team meetings to discuss the various patients / cases will continue in the current format, while team commitments and benefits are perceived as well balanced. Benchmarking with other paediatric palliative care services within Australia and New Zealand is also possible pending development of the appropriate data sharing agreements.

Figure 7 Lessons learnt

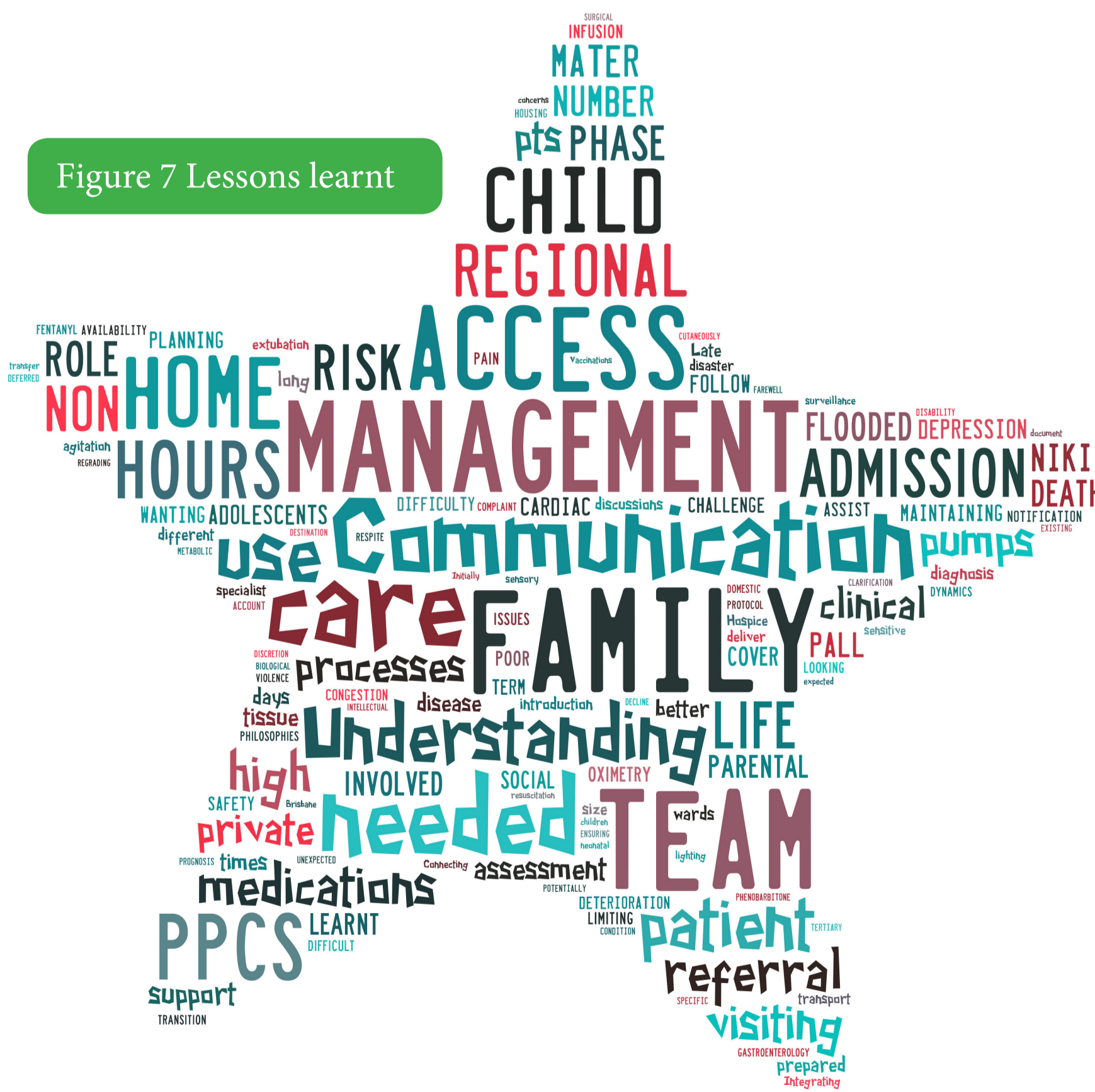


Figure 8 Things done well

Figure 1. Diagnostic category of referrals

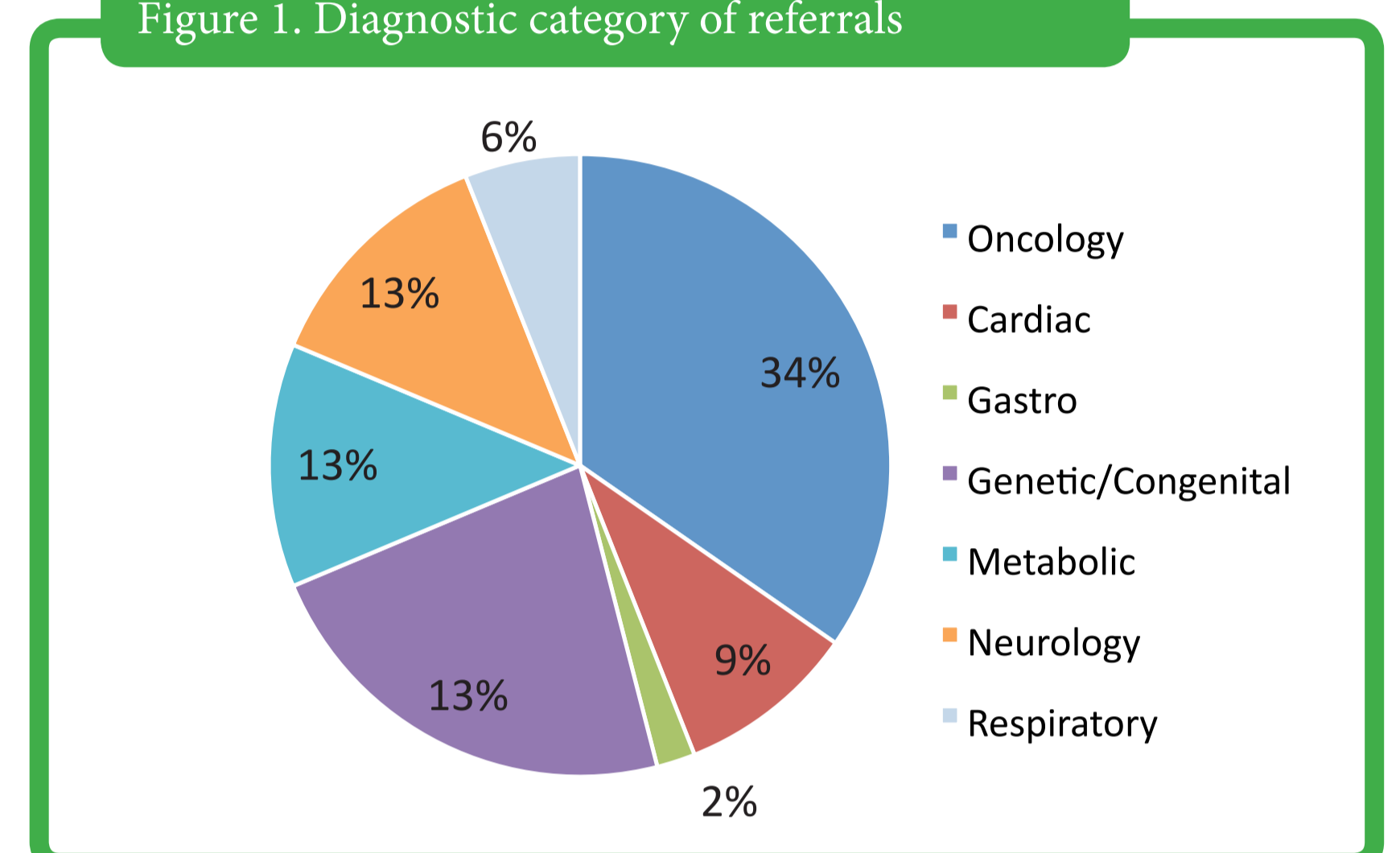


Figure 2 Age at time of death

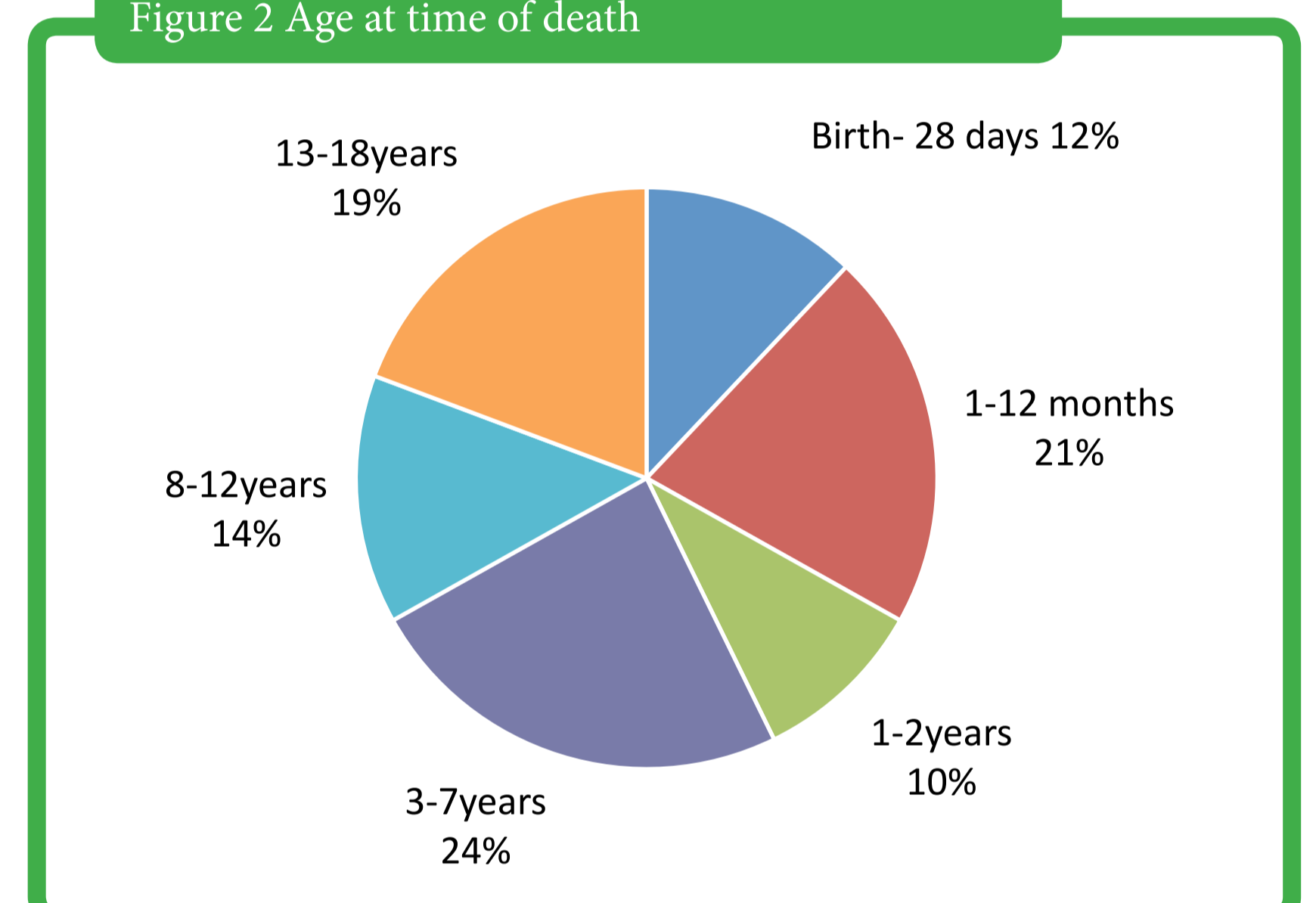


Figure 3 Location of residence

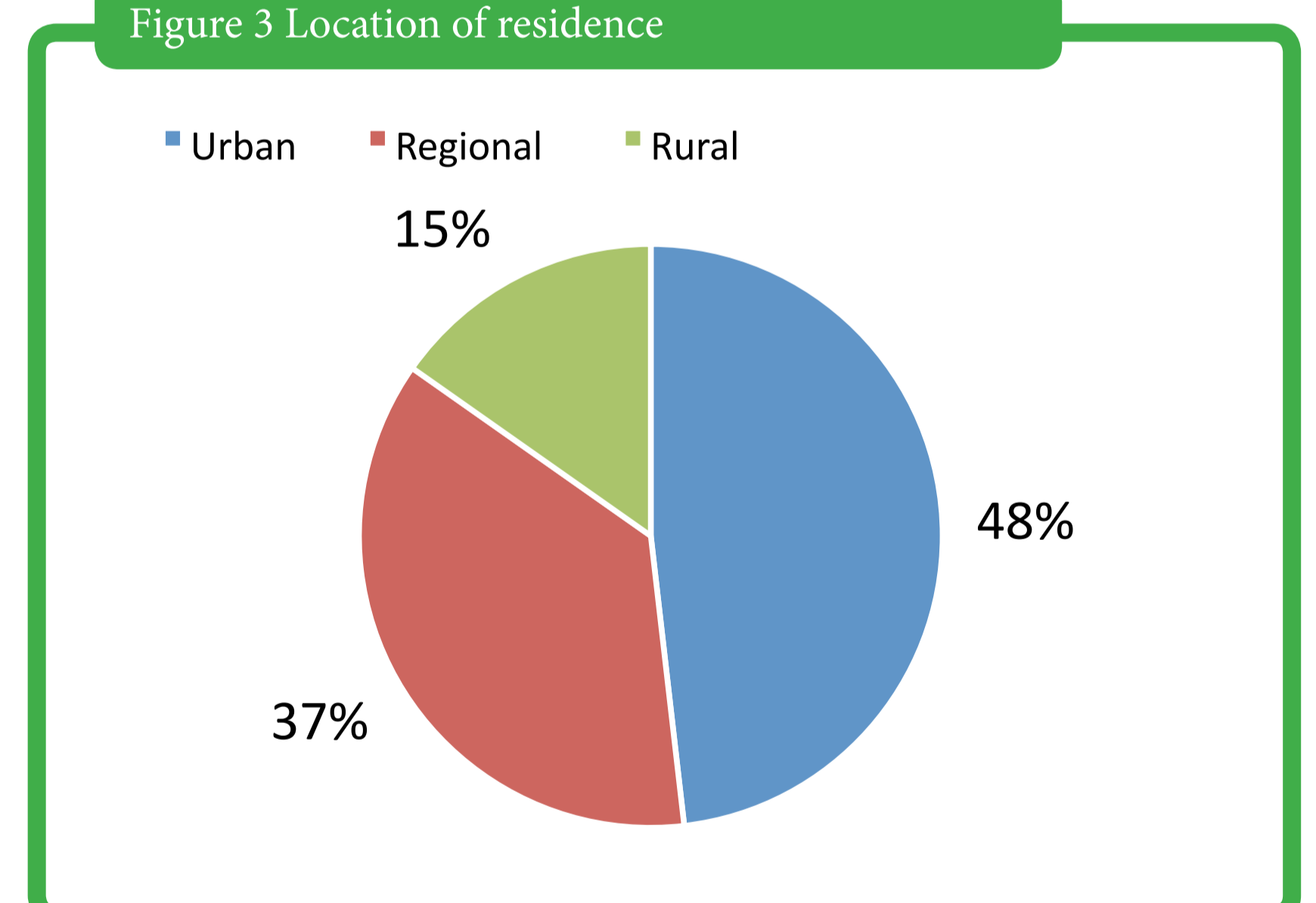
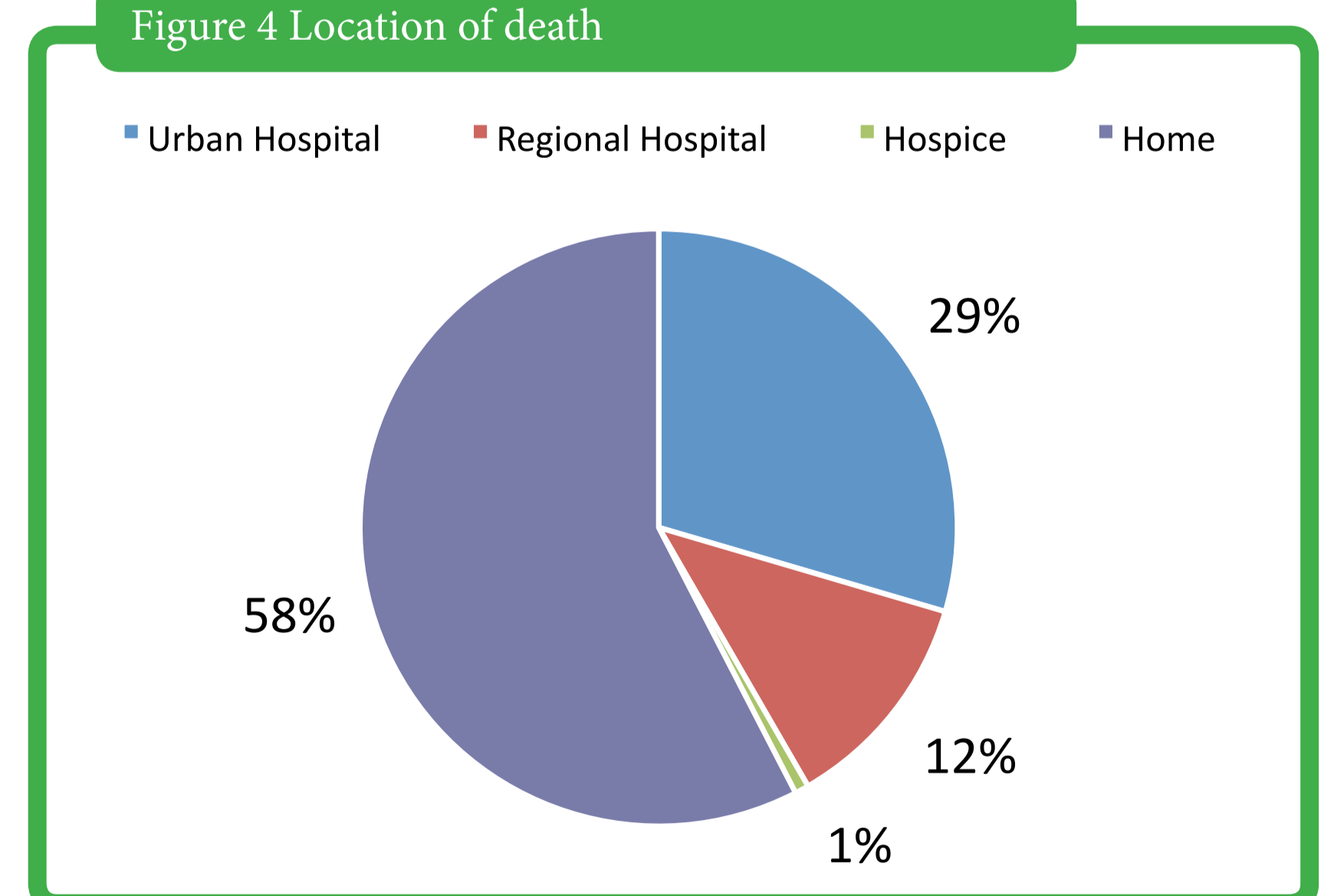


Figure 4 Location of death



Acknowledgements

To the parents who gave consent for their children's photos to be used and to the administration support staff that assisted with data entry.