

Pediatric Hospice Palliative Care Survey 2005: Highlights

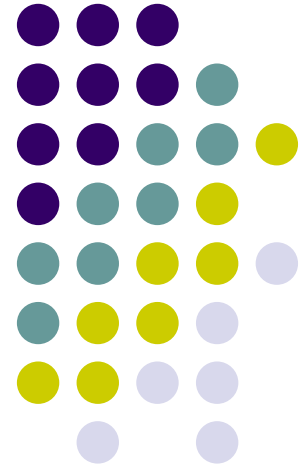


Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs



Canadian Network of Palliative Care for Children
Réseau canadien de soins palliatifs pour les enfants





Overview

- Pediatric Palliative Care is provided in a variety of ways across Canada, by individuals, groups and organizations. Services / care can be adult-based or pediatric-focused.
- 8 page survey – 30 questions
- Distributed Nation-wide via Provincial/Territorial Champions



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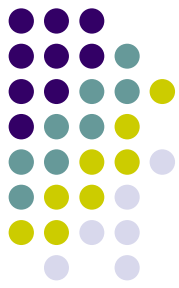
CNPCC Survey Champions



CNPCC - Survey Champions:	Province / Territory
Filomena Nalewajek	British Columbia
Lillian Rallison	Alberta
Donna Goodridge	Saskatchewan
Susan Fowler-Kerry	Saskatchewan
Brenda Peters-Watral	Manitoba
Maria Rugg	Ontario
Linda Côte-Brisson	Quebec

CNPCC - Survey Champions:	Province / Territory
Judy Clark	New Brunswick
Wendy Harris	New Brunswick
Mary Hughes	PEI
Simone Stenekes	Nova Scotia
Honna Janes-Hodder	Newfoundland & Labrador
Greg Adams	Yukon / NWT / Nunavut





Overview continued...

- Purpose: To gather national information about the delivery of services/care to children with life-threatening illnesses or life-limiting conditions. Includes:
 - services currently available to children and families who live with life-threatening illnesses or life-limiting conditions
 - families/individuals who have lost a child/sibling from any cause including perinatal losses (stillbirth, miscarriage or abortion).



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Overview continued...

- A picture of settings where services/care is currently being provided, including those where pediatric care is not the primary focus.
- Data to help with the design of services/care and to advocate for enhancement of Pediatric Palliative Care (PPC) services across Canada.
- Contacts for communication of information.



Pediatric Hospice Palliative Care Survey



- **OVERVIEW**
- **CONFIDENTIALITY *Statement***
- **CHARACTERISTICS Of The Organization**
- **SERVICE Provision**
- **SETTING *of Care***
- **CLIENT *Description***
- **STAFF *Education***
- **Other**





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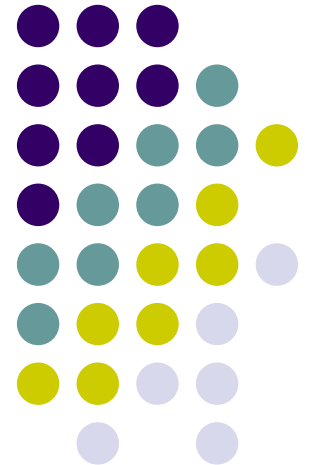


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Pediatric Hospice Palliative Care Survey 2005: RESULTS

Check the CNPCC Website @

www.cnpcc.ca





Highlights of Results

- **229 Responses Received**
 - **Information about the respondents: to be analyzed**



RESULTS:

Organizational Identification

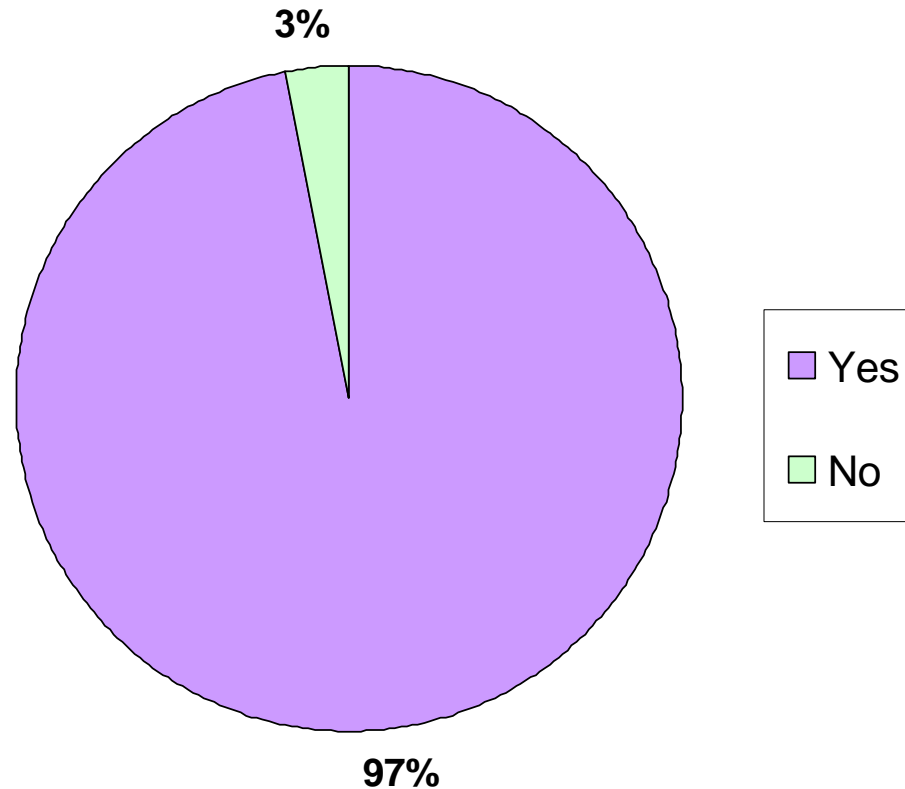


- Please indicate if we may contact you for further questions & updates:

Yes 97%

No 3%

- 200 Respondents answered / 9 Skipped the question



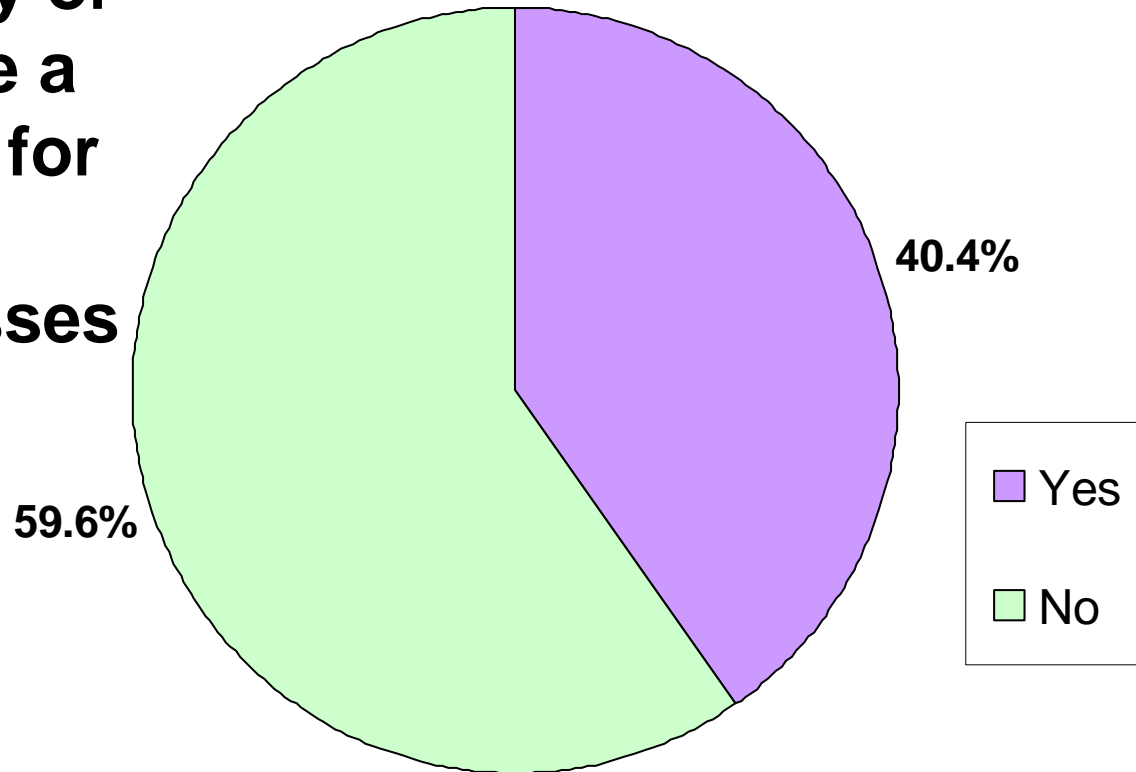
RESULTS:

Organizational Identification



- Does your agency or organization have a specific program for children with life threatening illnesses or life-limiting conditions?

- Yes 40.4%
- No 59.6%



● 218 / 11



RESULTS:

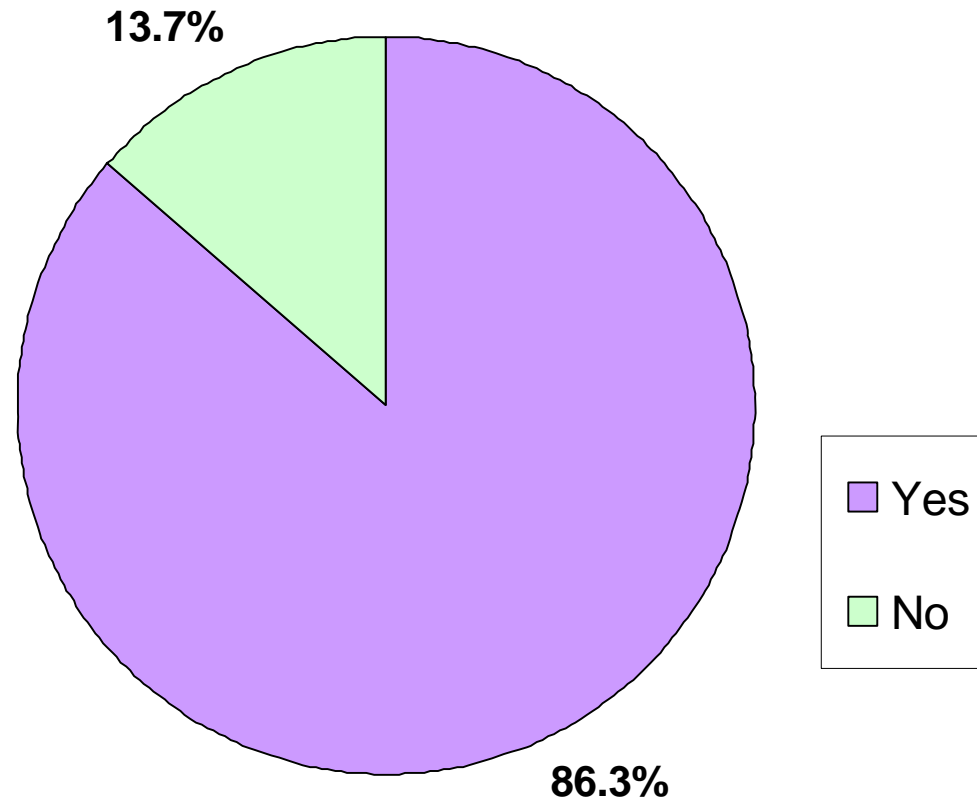
Service Provision



3. Does your agency or organization currently provide care &/or services to children with life-threatening illnesses or life-limiting conditions?

- Yes 86.3%**
- No 13.7%**

● **227 / 2**



RESULTS:

Service Provision

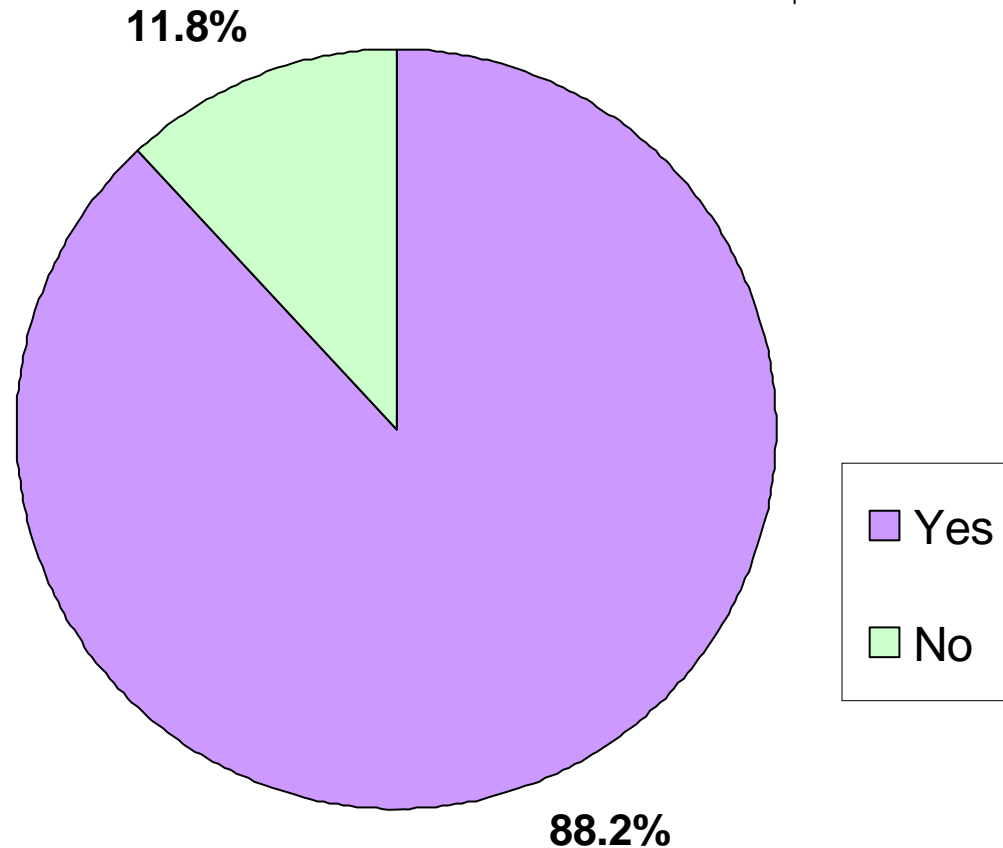


4. Has your program provided care and/or services to children and /or families in the past three (3) years?

Yes 88.2%

No 11.8%

● **228 / 1**



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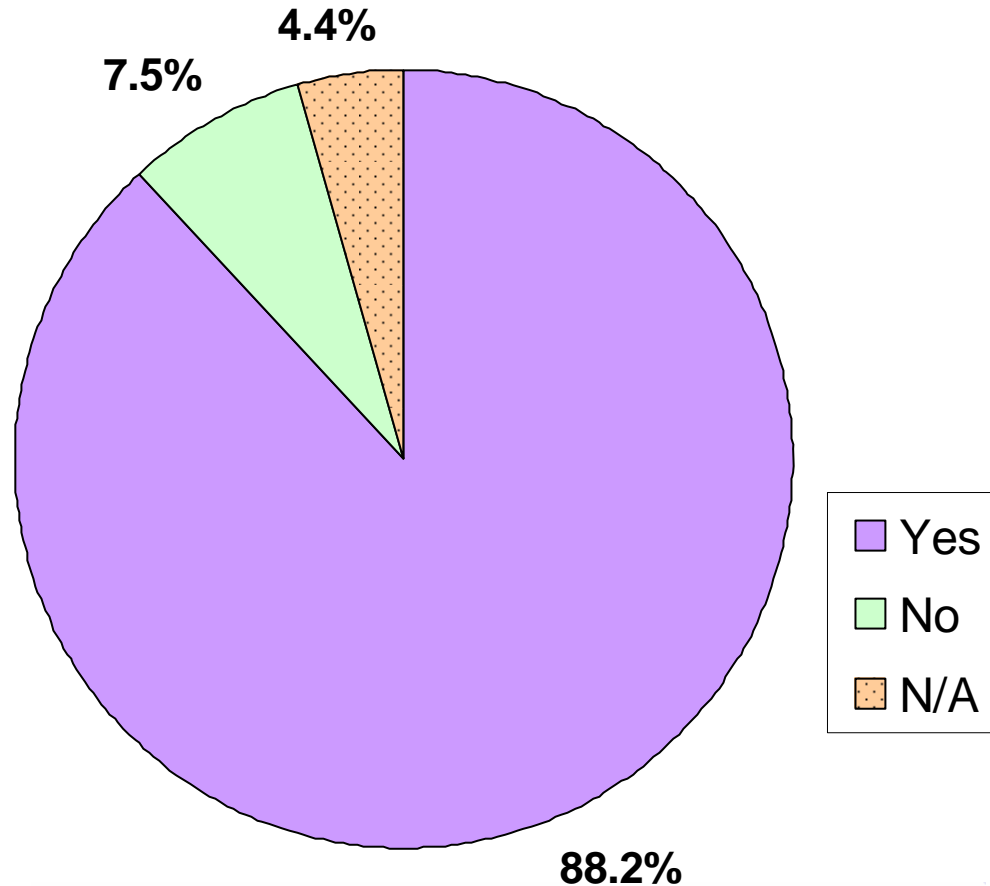
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RESULTS: Service Provision



5. Is your program planning on providing care/services to children with life threatening illnesses or life-limiting conditions in the future?

- Yes 88.2%**
- No 7.5%**
- N/A 4.4%**
- 228 / 1**



RESULTS:

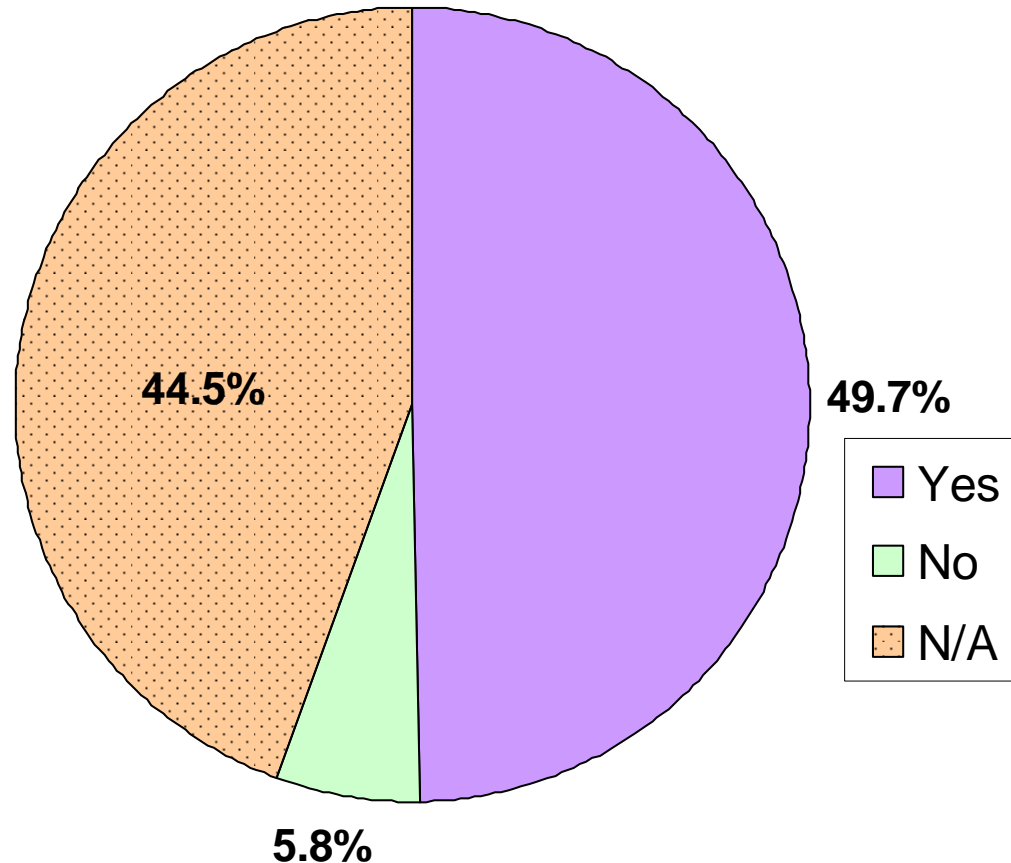
Service Provision



- If your team /agency /program **DOES NOT** regularly provide care to children with life-threatening illness, do you know how to access such care for a child /family living in your area?

- Yes 49.7%
- No 5.8%
- N/A 44.5% - provide services, but does not apply

● 173 / 56



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RESULTS:

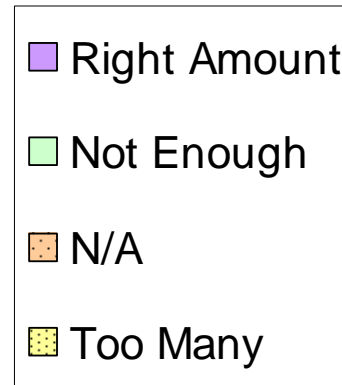
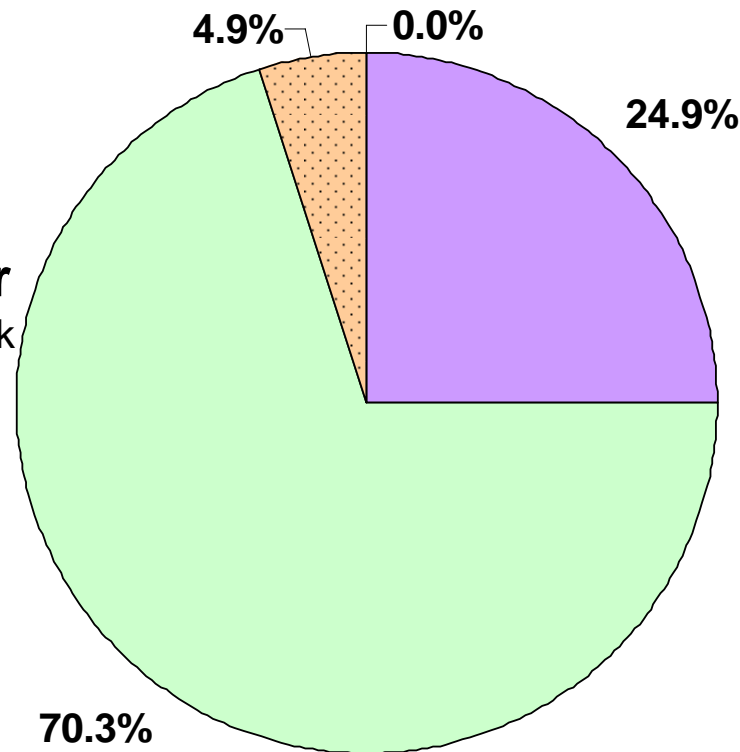
Service Provision



- In your area, do you believe that there are enough services available for children with life-threatening illness, either from what your team /agency/ program offers or what is available from other nearby organizations? Check one

- Right amount of services are available 24.9%
- Not enough services available 70.3%**
- Too many services are available 0%
- N/A 4.9%

● **185 / 44**



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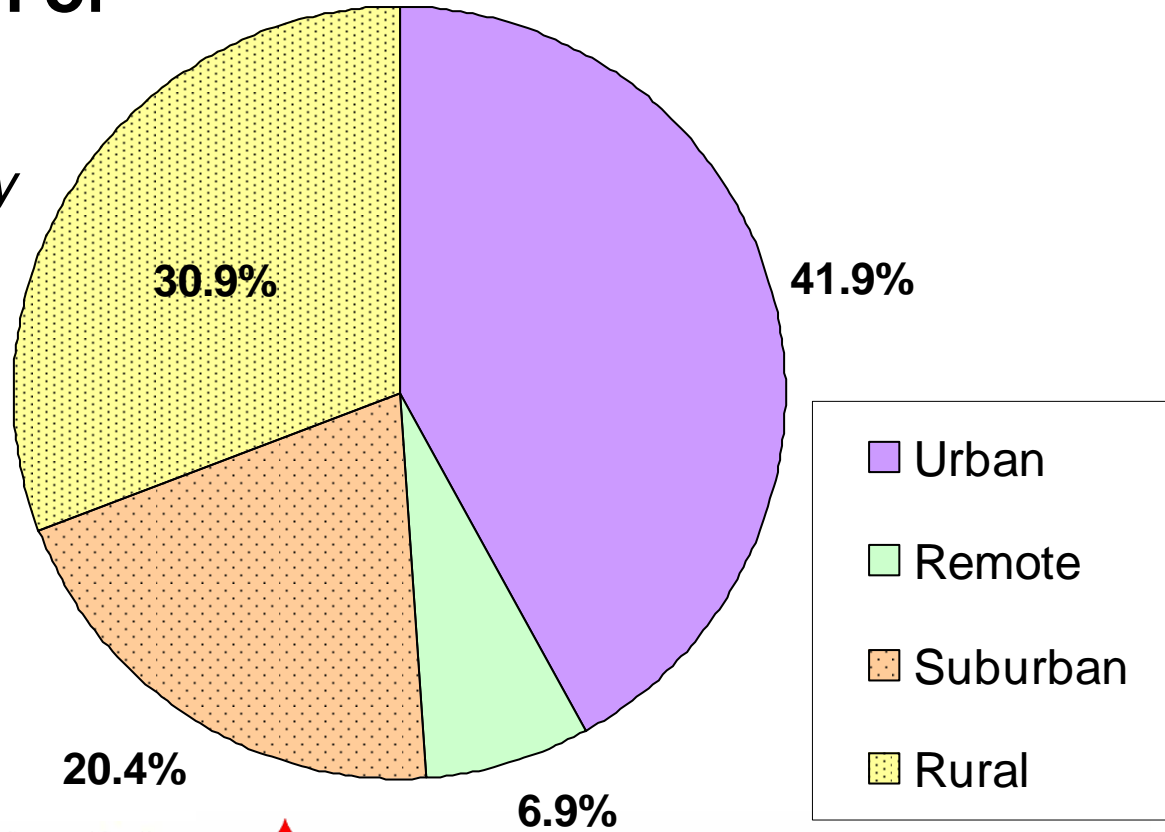
Profile of Respondents: Characteristics of agency/service



8. Setting/Location of Care / Services:

Please check all that apply

- Urban 68.2%**
- Remote 11.2%
- Suburban 33.2%
- Rural 50.2%**
- **223 / 6**



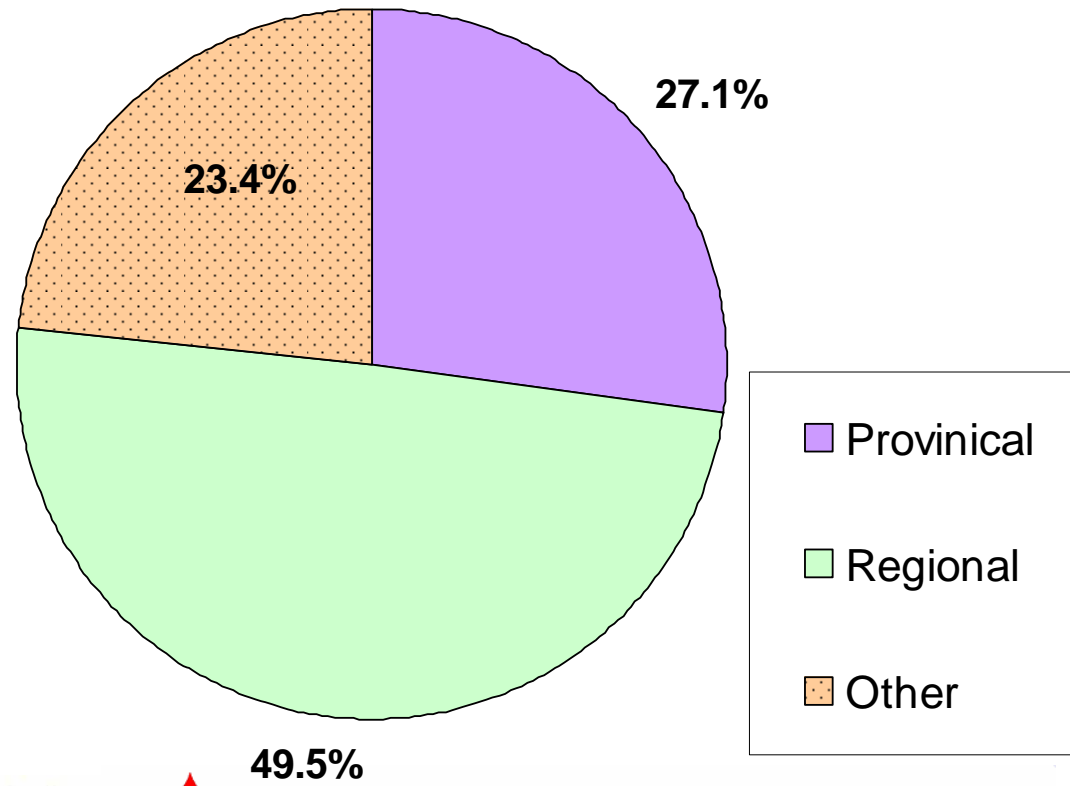
Profile of Respondents: Characteristics of agency/service



8. Type of Program:

Please check all that apply

- Provincial Program
27.1%
- Regional Program
(for provinces with
regions) 49.5%
- OTHER 23.4%
- 216 / 13



Patients / Clients Receiving Pediatric Palliative Care



13. Description of the patients / clients that receive your care and/or service *Check all that apply*

- 210 respondents / 19 skipped question
- 82.9% Children with any life-limiting/ life-threatening disease or condition
- 22.4% Children with cancer only
- 46.2% Children with disease(s) other than cancer
- 82.4% Parents
- 70% Siblings



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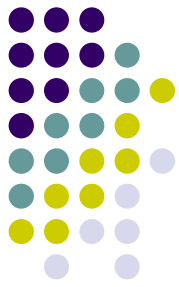
Patients / Clients Receiving Pediatric Palliative Care con't.



13. Description of the patients / clients that receive your care and/or service *Check all that apply*

- 49% Extended family
- 30.5% Friends, classmates
- 42.4% Health care providers to the child
- 26.7% Non-health care providers to the child
- 14.3% OTHER



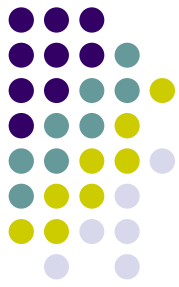


Patients Ages – able to serve

- 211 Respondents / 18 skipped the question

Age Category	%
Prenatal	26.5%
Neonates (birth - 30 days)	64.5%
Infants (31 days to 1 year)	75.4%
Children (1 year to 12 years)	88.6%
Youth (13 -18 years)	85.8%
Youth (over 18 years)	63.0%

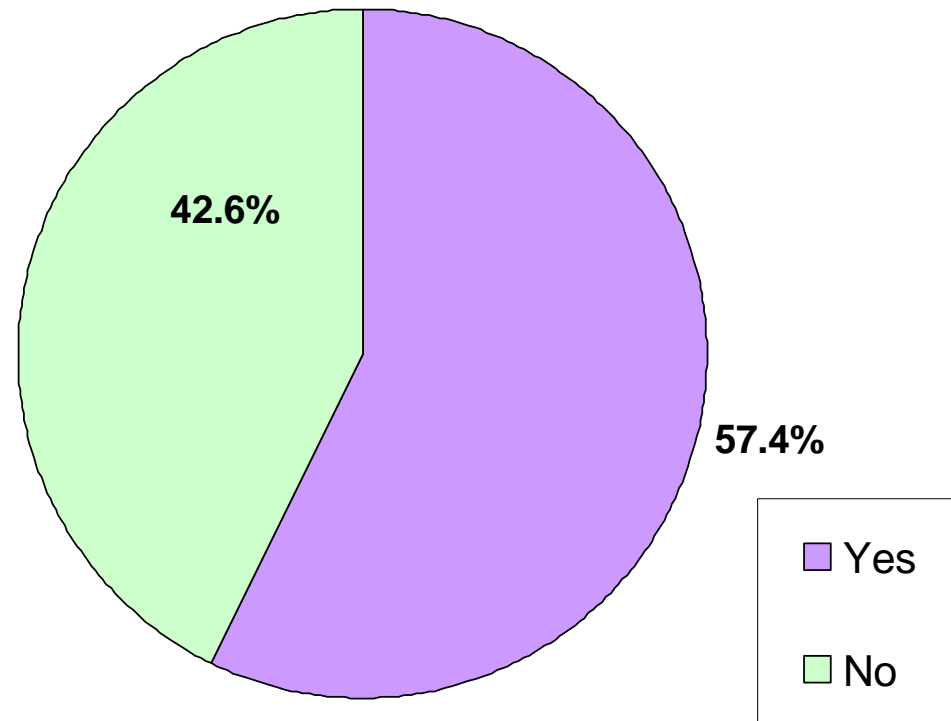




Data kept?

15. Does your organization or agency maintain statistics, a database or quality improvement information that would provide information about patients /clients served?

- Yes 57.4%**
- No 42.6%**
- **197 / 32**



Program Development and Service Needs



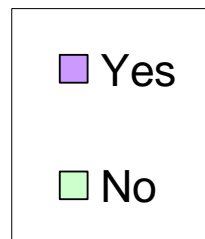
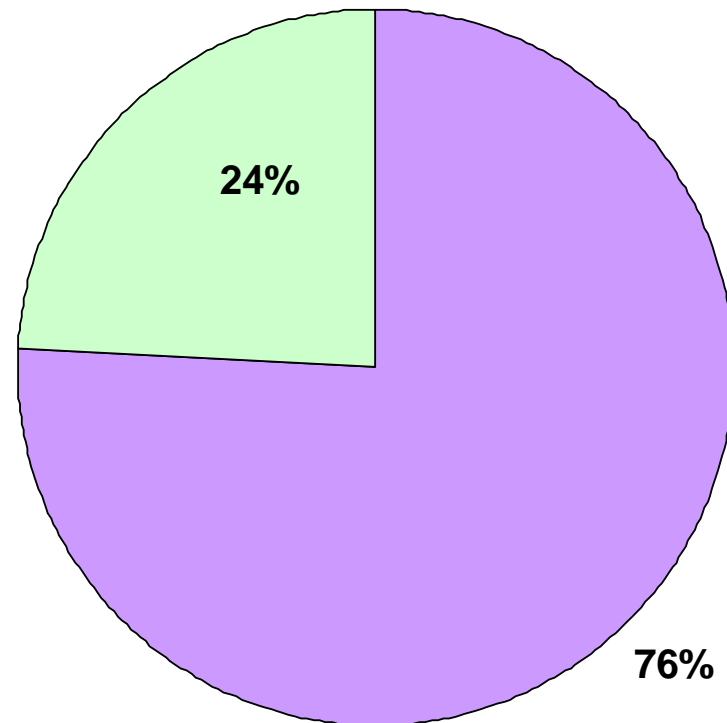
18. Does your staff:

a) participate in education related to the care of children with life-threatening illness?

Yes 76%

No 24%

● 217 / 12

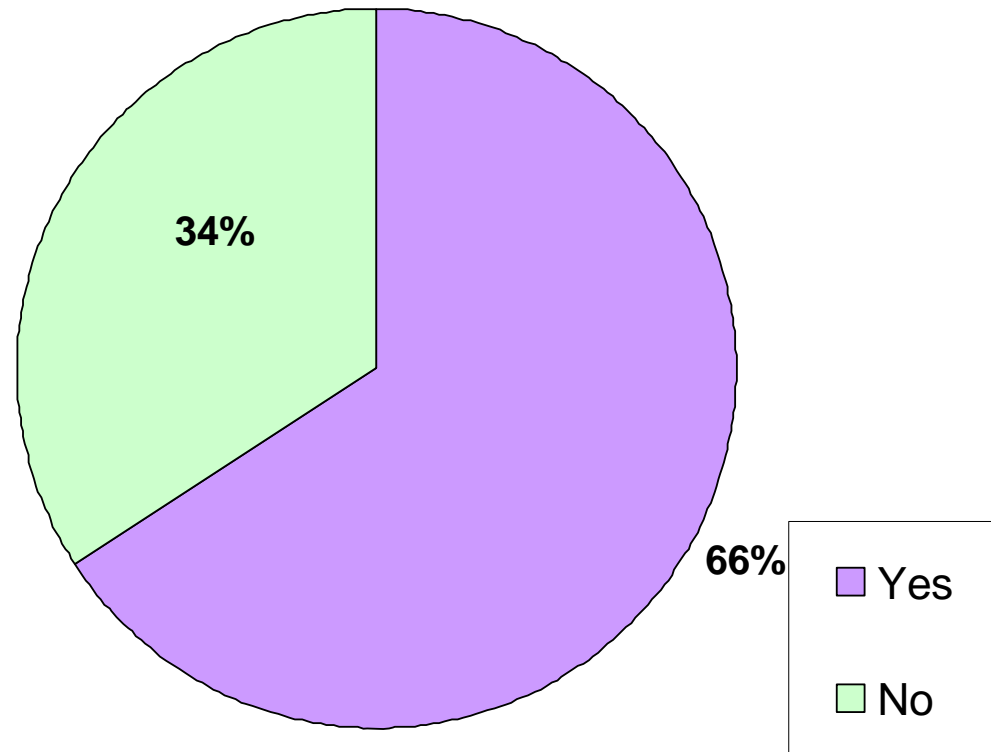


Program Development and Service Needs



18. Does your staff:
b) *provide* education related to the care of children with life-threatening illness?

- Yes 66%
- No 34%
- 117 / 112



Program Development and Service Needs

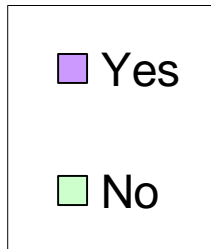
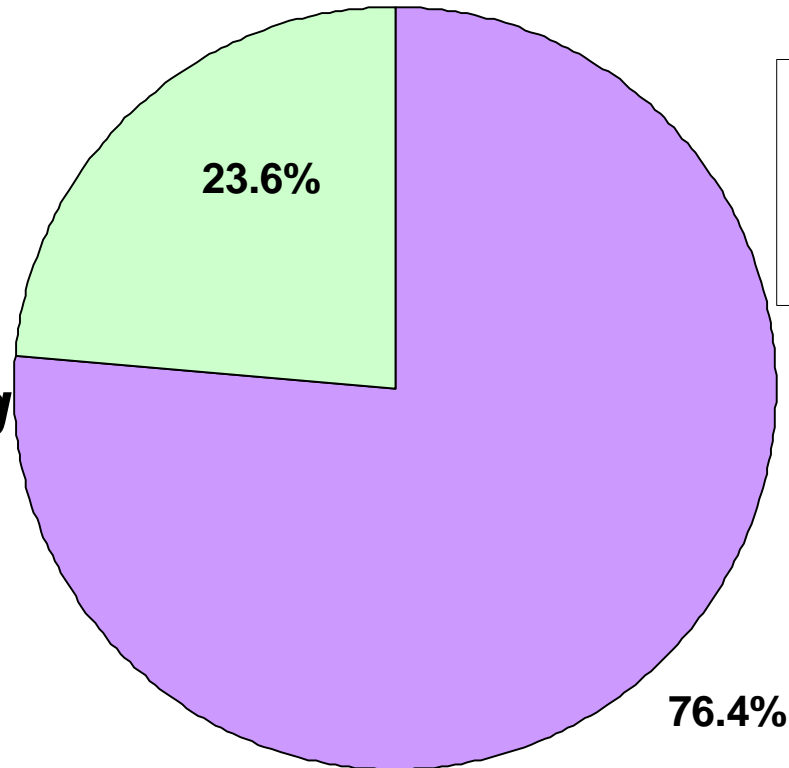


19. Has your direct care staff accessed education in the specific area of care of children with life-threatening illness through workshops, conferences or participation in continuing education programs?

Yes 76.4%

No 23.6%

● 212 / 17



Program Development and Service Needs

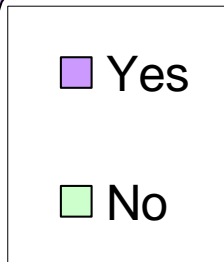
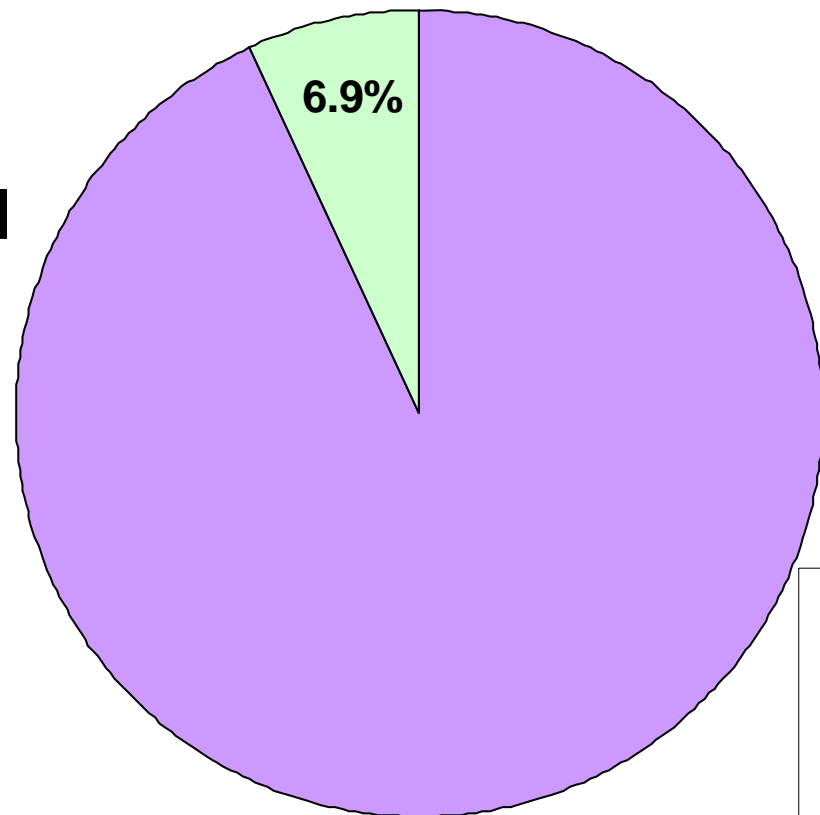


20. If education in care of children with life-threatening illness were available, would your team/ agency /program take part?

Yes 93.1%

No 6.9%

● **216 / 13**



93.1%





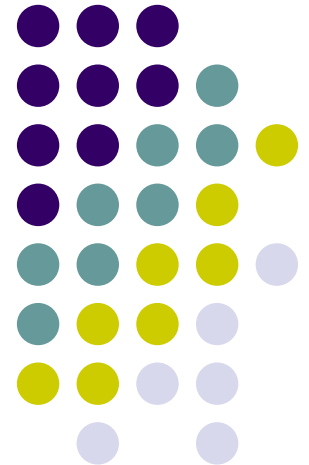
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Acknowledgements



Thank You



- Survey Respondents
- CNPCC Executive & Survey Champions



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QUESTIONS ?

