TOWNSVILLE PALLIATIVE CARE COMMUNITY SURVEY REPORT

Connecting End of Life Care in Townsville Project (CELC-T)

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PALLIATIVECAREQLD.ORG.AU/CELC

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Townsville CELC
CONNECTING END OF LIFE CARE

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1. EXECUTIVE SUMMARY

This report presents the findings of a community focused palliative care community survey (The Survey) conducted in Townsville in 2018. The purpose of this community focused survey was to explore Townsville's:

- Public knowledge about palliative care
- To gain an understanding about how the Townsville public are accessing and sharing information about palliative care
- Promote awareness of palliative care

The Survey was conducted as part of the Connecting End of Life Care in Townsville (CELC-T) project administered by Palliative Care Queensland and funded by the Australian Government through the Primary Health Network projects. The Survey was rolled out in parallel with a Training Needs Analysis of Townsville aged care facility staff.

The Surveys were open from 14th February to 2nd April 2018 and compromised a range of activities designed to maximize opportunities for community to participate. Activities particularly focused on social media promotion and an incentive prize to complete the survey. A total of 337 completed the survey and the social media reach was over 6,500.

Key findings of the survey included:

- 60% indicated they learned about palliative care through their personal experience and the next highest response was through friends, families and coworkers
- 50% of respondents rated *good* on their current knowledge about palliative care
- The majority (46%) of respondents indicated that they are *'reasonably confident'* about both having a conversation and accessing information and support about palliative care and end of life issues
- 82% respondents would choose quality of life over length of life.

In addition, 'Grey feedback' received from social media engagement indicated that health professional's explanations and approach to end of life care were not always understood by community members.

Four key recommendations were identified for the next stage of the CELC-T project:

1. Build community confidence to source palliative care information and services, to ensure the information they source is accurate and relevant to their needs.
2. Build on the community confidence in facilitating conversations about end of life to empower the community to initiate these conversations with health professionals.
3. Improve health professional's ability to explain the process of end of life care
4. Share patient experiences and stories about end of life

2. BACKGROUND

Palliative Care Queensland (PCQ) is a state-wide independent, not-for-profit peak body representing palliative care providers, consumers and their families and those with an interest in palliative care.

Connecting End of Life in Townsville project (CELC-T) is administered by PCQ, funded by North Queensland Primary Health Network (NQPHN) and working in collaboration with the Townsville Palliative Care Service at Townsville Hospital and Queensland Health Centre for Palliative Care Research and Education (CPCRE).

The survey was conducted as part of the Connecting End-of-Life Care in Townsville (CELC-T) project. The CELC-T project aims to improve the capacity of aged care and general practice service providers within The Greater Townsville region, to provide quality palliative care and end-of-life planning, thereby assisting in the management of after-hours service need.

CELC-T project is being conducted over an eighteen-month period and is concentrating on building connection between end-of-life services and community groups by improving culture, systems and practice.

The Greater Townsville region is defined as those communities in the Townsville Local Government Area.

End-of-life care includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events. [1]

[1] *Essential elements for safe and high-quality end-of-life care* (ACSQHC 2015)

Palliative care (often formally referred to as palliative approach) is an approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual). [1]

Specialist palliative care is care that focuses on complex issues related to life-limiting illness; this may include complex symptom management, complex conversations and complex planning. Services that are provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care. [1]

Note regarding definitions

The terms 'end-of-life care' and 'palliative care' tend to be used interchangeably. The ACSQHC makes note of two different components of the end-of-life definition: likely to die in the next 12 months (involving periods of exacerbated illness that may be reversible); and likely to die in the short term (within days to weeks), where clinical deterioration is likely to be irreversible. In contrast, palliative care may not be limited to the last 12 months of life—the need for palliative care may be episodic over an extended period, depending on the illness.

3. METHODOLOGY

SURVEY DEVELOPMENT

A desktop review of community palliative care surveys was conducted and The Survey questions and topics were adapted from five different surveys:

1. Queen's university Belfast: Exploring public awareness and perceptions of palliative care: a qualitative study (2014)[2]
2. Powell River Hospice Society and Powell River Division of Family Practice: Palliative Care Community Survey (2017)[3]
3. Hospice New Zealand: Public perceptions of hospice and palliative care and attitudes to death and dying survey (2010)[4]
4. Scottish Partnerships for Palliative Care: Public awareness of palliative care[5]
5. Palliative Care Australia website community Polls[6]

Due to the short timeframe of the project The Survey was conducted as Quality Improvement Activity rather than a research project and The Survey questionnaire was developed and reviewed by the PCQ staff team, along with a draft survey shared with a small number of Palliative Care Queensland members for feedback and review. Feedback provided the basis for the final survey.

The complete survey is included as Appendix 1.

SURVEY DISTRIBUTION

Palliative Care Queensland utilised a range of distribution methods, which included on-line and hardcopy versions of surveys.

Information flyers and hard copies of The Surveys were distributed with large collection boxes by members of the CELC-T project steering committee to community venues and aged care facilities.

[2] McIlfatrick, S., Noble, H., McCorry, N. K., Roulston, A., Hasson, F., McLaughlin, D., ... Craig, A. (2014). Exploring public awareness and perceptions of palliative care: a qualitative study. Palliative Medicine, 28(3), 273-280. DOI: 10.1177/0269216313502372

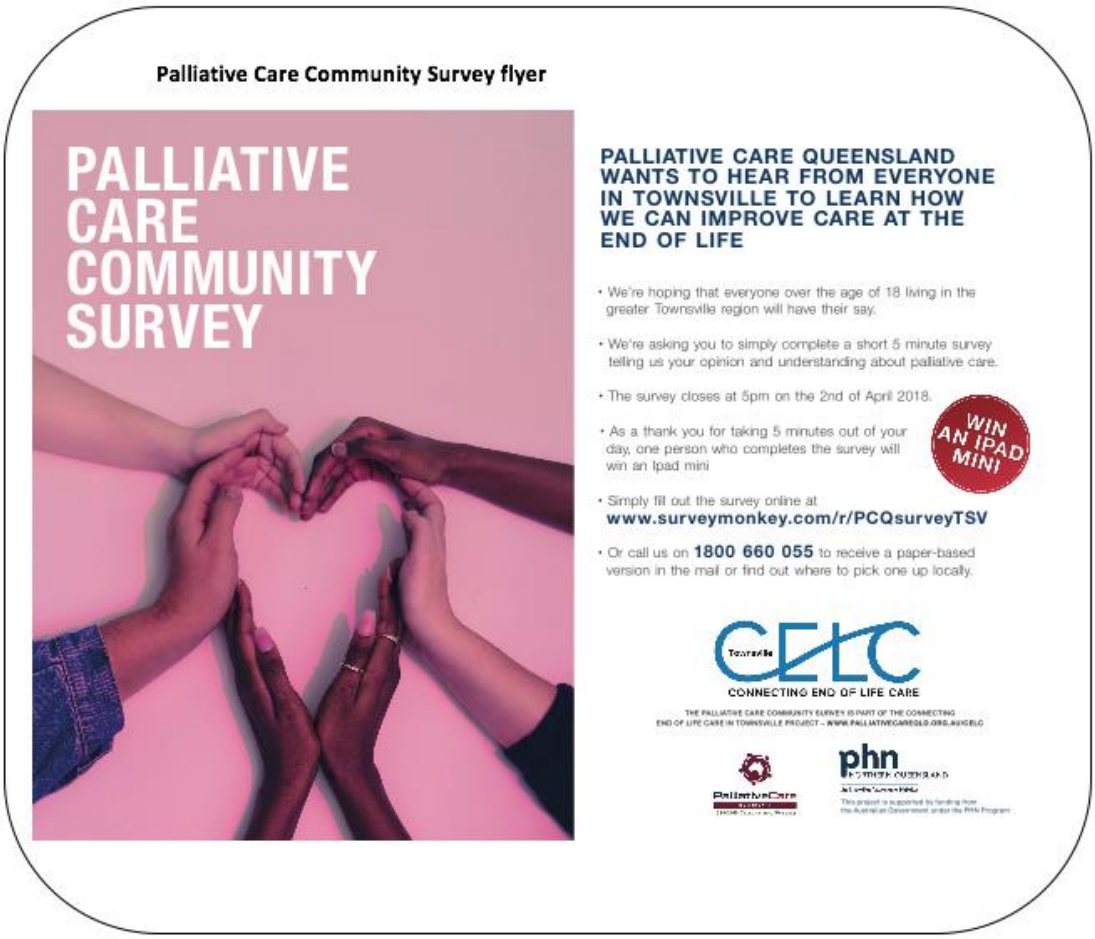
[3] Powell River Hospice Society and Powell River Division of Family Practice: Palliative Care Community Survey (2017) downloaded on January 20th 2018 from *https://prhospice.org/wp-content/.../Palliative-Care-Community-Survey-Summary.pdf*

[4] Hospice New Zealand: Public perceptions of hospice and palliative care and attitudes to death and dying survey (2010) downloaded on January 20th 2018 from *www.hospice.org.nz/cms_show_download.php?id=127*

[5] Scottish Partnerships for Palliative Care: Public awareness of palliative care downloaded on January 20th 2018 from https://www.palliativecarescotland.org.uk/content/publications/PublicAwarenesso-PalliativeCare.pdf

[6] Palliative Care Australia website community Poll's downloaded on January 20th 2018 from http://palliativecare.org.au/polls

Palliative Care Community Survey flyer



The Survey was mainly promoted via social media. Social media promotional items (including images and videos) along with hyperlinks to The Survey tool were posted and promoted on the PCQ website and social media platforms including:

- Facebook
- Twitter

Palliative Care Community Survey twitter and Facebook promotional material



Facebook social media was also sponsored to target Townsville population.
MP Cathy O'Toole and the Townsville Council promoted The Survey on their website and via social media.

SURVEY DATA COLLECTION

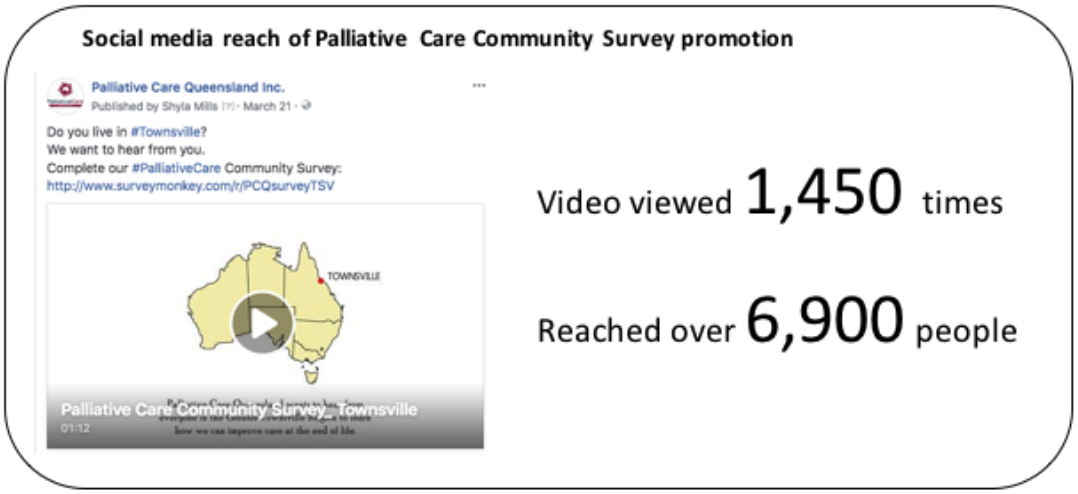
Data collection period was from 14th February 2018 to 2nd April 2018. A total of 337 surveys were collected and collated using the survey monkey platform.

Average time to complete the survey was 5 minutes. As an incentive to complete the survey, participants were given the chance to win a mini-iPad valued at $300. This prize was sponsored by PCQ.

SOCIAL MEDIA ENGAGEMENT

Social media engagement was conducted via the PCQ Facebook page and via Twitter. This strategy enhanced the reach of the promotion of the CELC-T project and allowed for community members to actively participate in conversations about palliative care.

Our largest response was from the Facebook Video which was viewed 1450 times and reached over 6,900 people. The twitter promotion recorded 211 impressions.



PROJECT CONFIDENTIALITY

Palliative Care Queensland regards the confidentiality of the survey data to be of utmost importance.

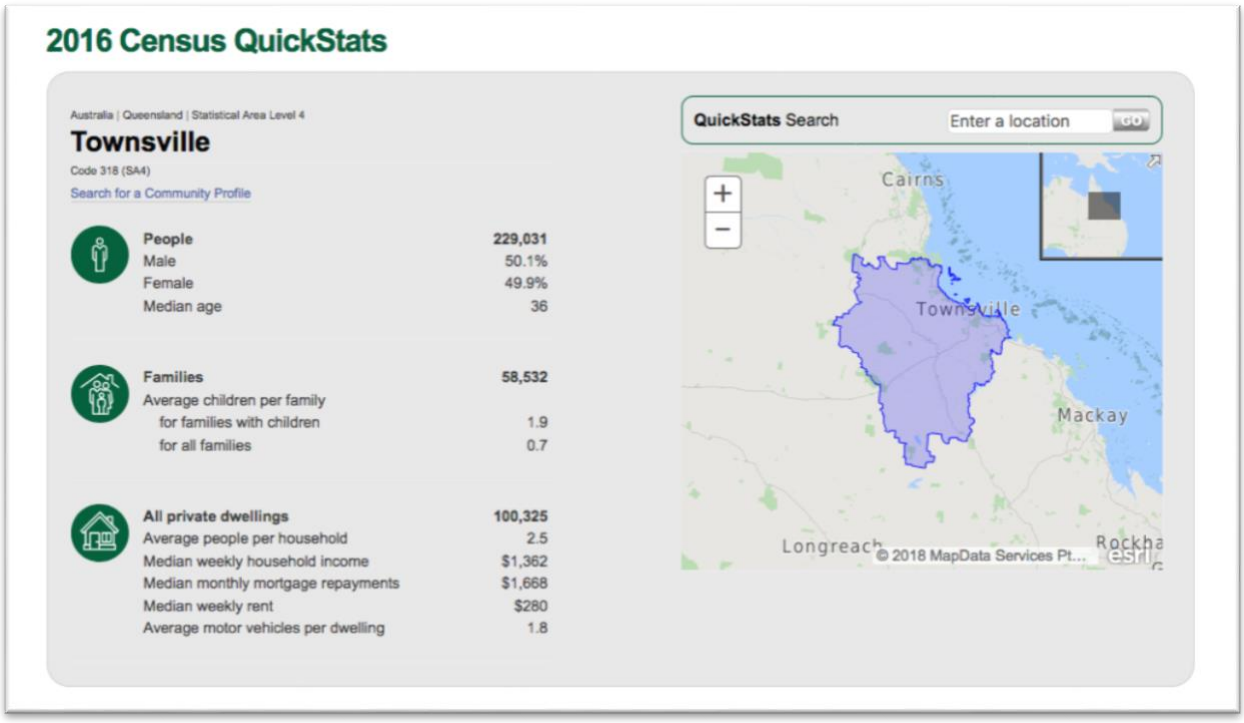
Data was collected on SurveyMonkey and paper based versions were inputted by Project Coordinator and Administration staff. No personally identifiable information is presented in the report. Additionally, the responses are combined and summarized in a report to further protect respondent's anonymity.

4. KEY FINDINGS / RESULTS

In total, 337 completed surveys were received during the engagement period. While this is not a statistically representative sample of overall Greater Townsville community, every effort was made to gather feedback from across a broad spectrum of Townsville community and to ensure as balanced a sample possible across demographic range.

DEMOGRAPHICS PROFILE

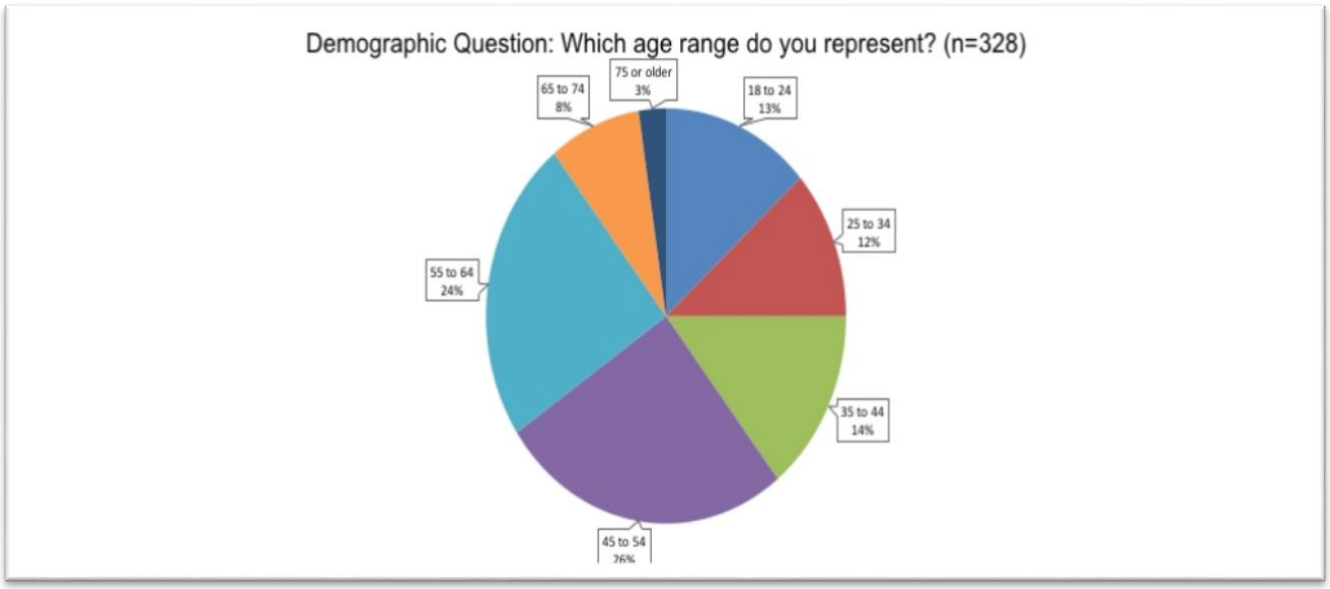
According to 2016 Census data, Townsville's[7] total population is 229,031; of these 50% male and 49.9% were female. To ensure that the sample was demographically representative, the survey questions included confirmation of age, gender and postcode.

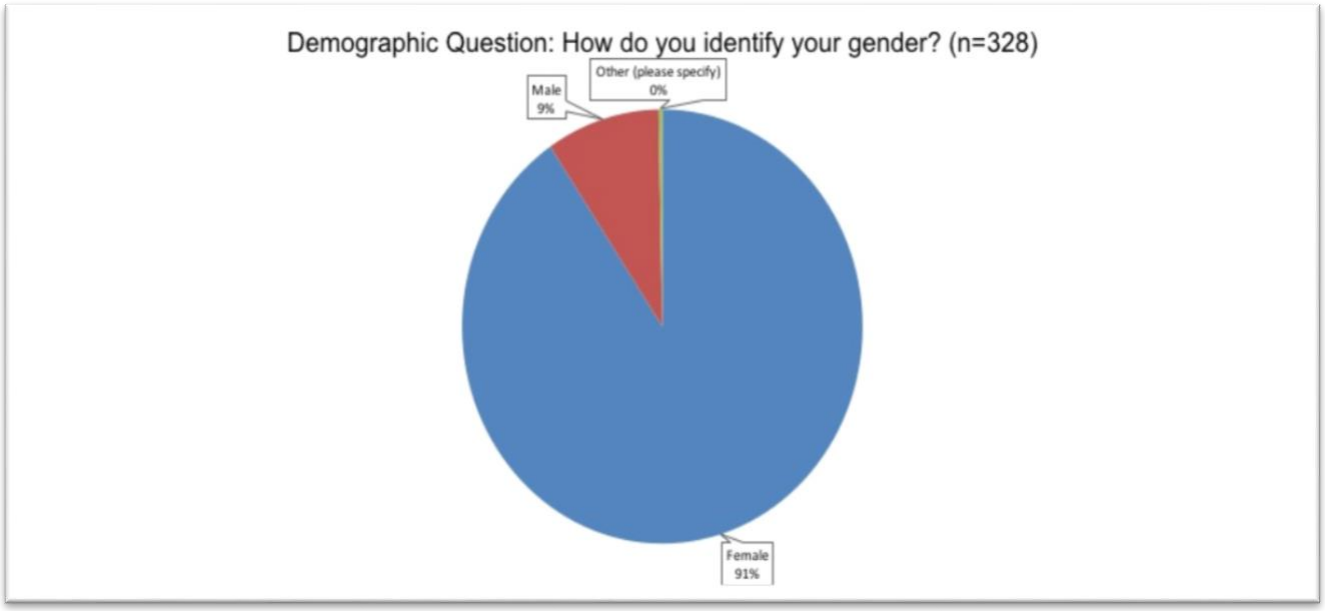


[7] Australian Bureau of Statistics (2016) 2016 Census QuickStats. Accessed on May 25, 2018 from http://www.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/318

GENDER AND AGE

Most respondents (91%) were female, half of the respondents were 45 - 65 years old.





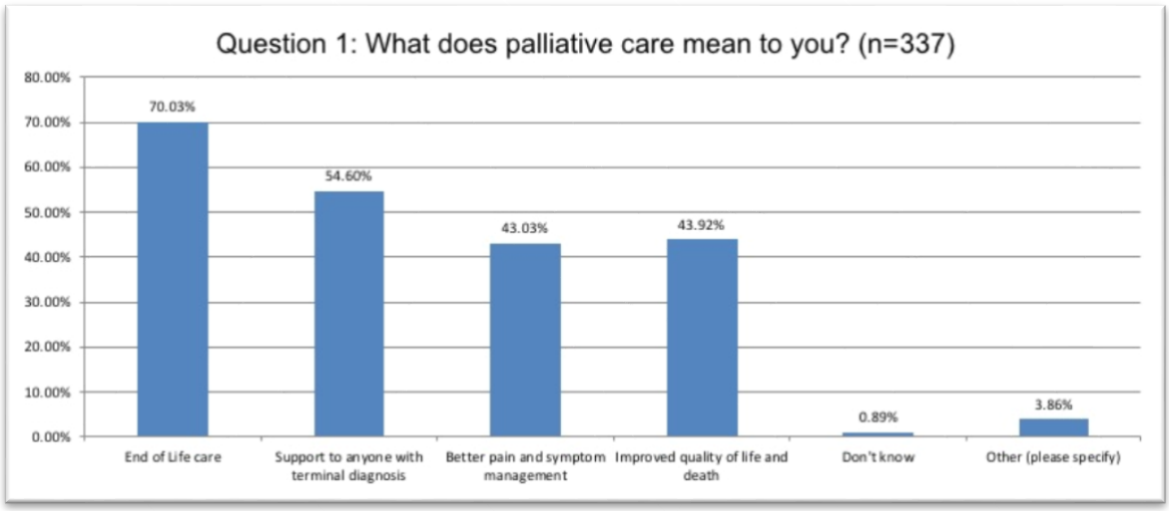
SURVEY QUESTION RESULTS

QUESTION 1: DEFINING PALLIATIVE CARE

This question aimed to gain an understanding of how the Townsville community define and communicates what palliative care is. Nil options were incorrect.
70% of respondents indicated palliative care means end of life care and less than 1% indicated they did not know what palliative care meant. Although there wasn't an option for "all" many people used the comment section to define "all of the above".

Additional comments defined palliative care as:

- *"maximise the quality of your last few weeks"*
- *"was very individual, every patient is different"*
- *"provides patients and families with support to help with what they are going through".*
- *"was Peace if possible"*
- *"making an individual as comfortable as possible and managing pain for end of life"*
- *"I have found in my experiences the one thing in common is no one wants to experience pain"*



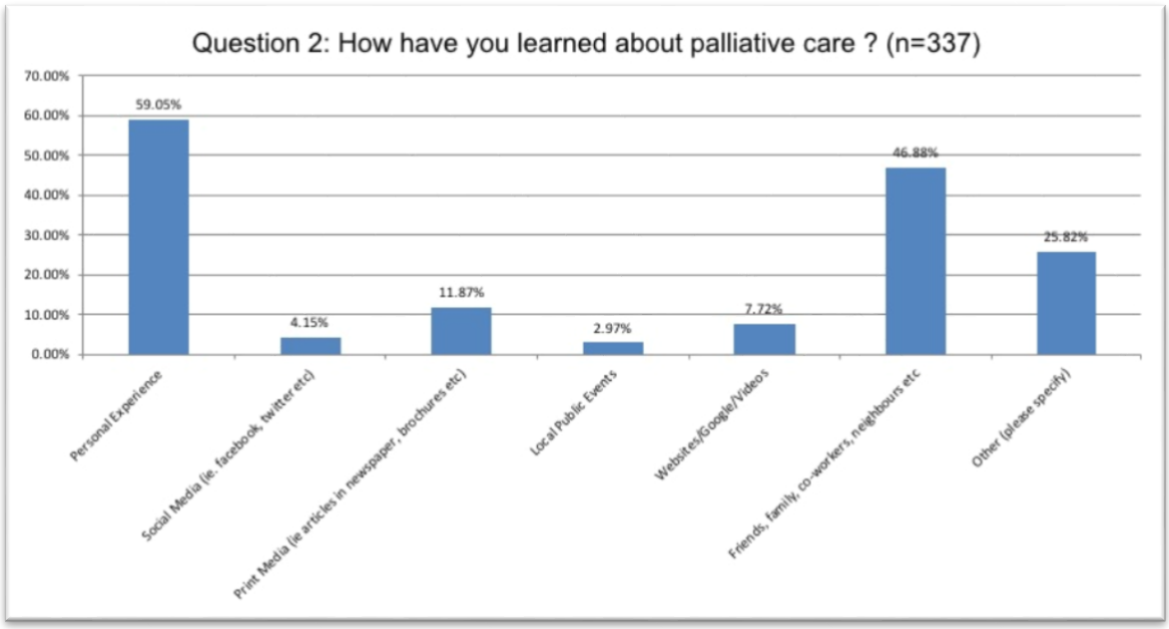
QUESTION 2: GAINING KNOWLEDGE ABOUT PALLIATIVE CARE

The purpose of this question was to gain an understanding of where community members gather their information from, to identify the best placement for services to provide information and resources or target supports.

59% indicated they learned about palliative care through their personal experience and the next highest response was through friends, families and co-workers.

A high number of respondents (25%) indicated “Other” and 87 comments were received – the key responses included:

- *Reading of books*
- *Completion of courses (inc university, TAFE or online)*
- *Working or volunteering in health care (inc aged care)*
- *Direct from health professionals (such as Doctor)*



QUESTION 3: CURRENT KNOWLEDGE

The purpose of this question to gain an understanding of how community members rate their current level of knowledge of palliative care.

50% of respondents rated *good* on their current knowledge about palliative care.

The other 50% were divided evenly been *very good* and *poor*.



QUESTION 4: CONFIDENCE IN ACCESSING INFORMATION

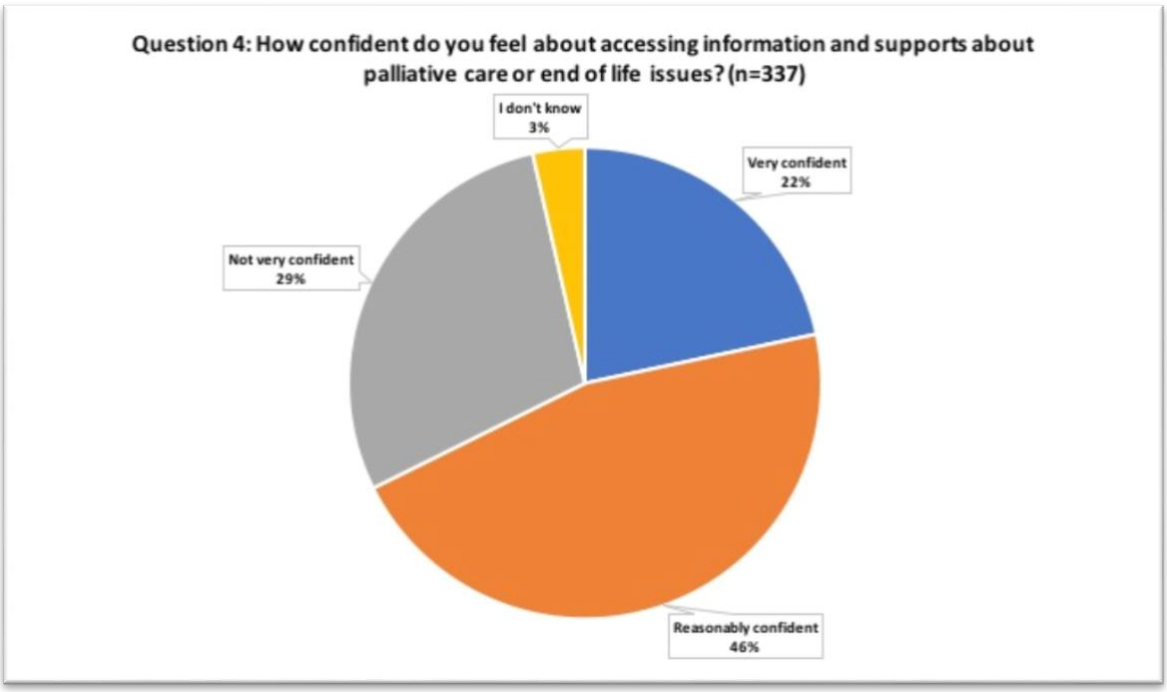
The aim of this question was to understand their level of confidence in accessing information and support about palliative care.

46% of respondent indicated that they are *'reasonably confident'* about accessing information and support about palliative care and end of life issues. One person noted they rated reasonably confident *"Only because I research info myself when my husband was diagnosed as being terminal"*

And 32% indicated they were not very confident or unsure of their confidence level.[8]

A respondent commented how they would access the information:

- *"I could always ring that department at hospital & ask what would be available & who to get onto about it."*



[8] "not very confident" levels are likely to be underrated due to an error in the survey tool

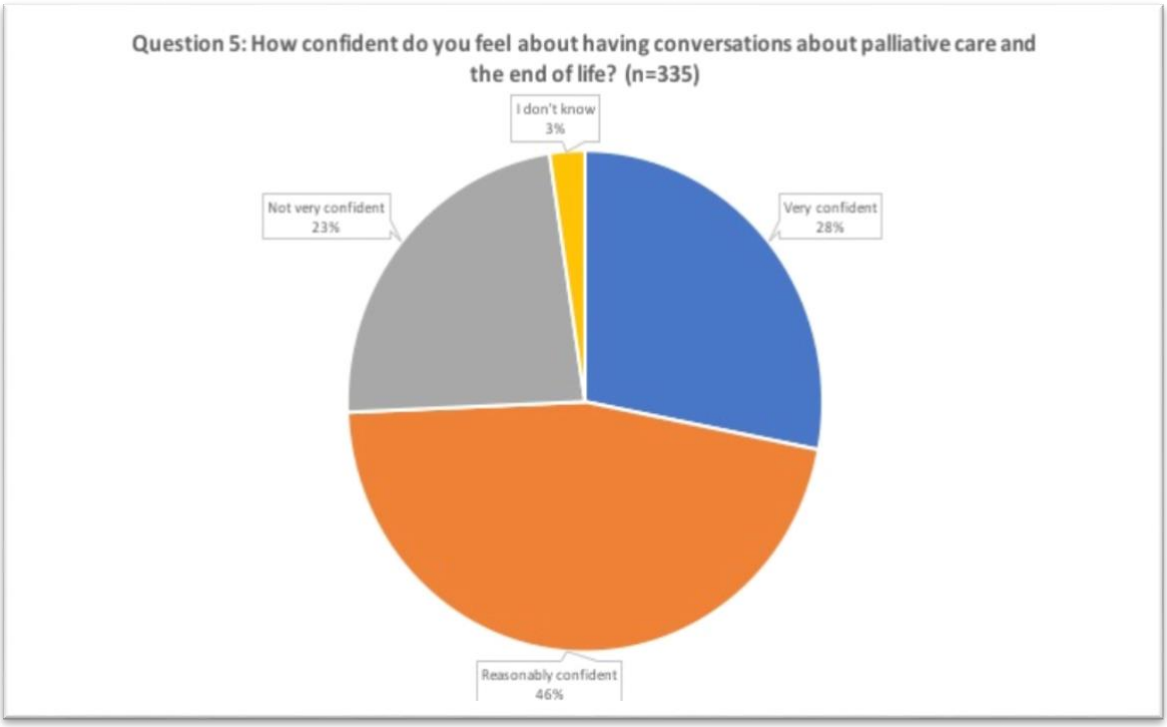
QUESTION 5: CONFIDENCE IN HAVING CONVERSATIONS

Communication is a large component of palliative care. This question aimed to understand how the community rated their confidence in having conversations about palliative and end of life care.

46% respondents indicated that they were *'reasonably confident'* to have a conversation about palliative and end of life care.

Some comments included:

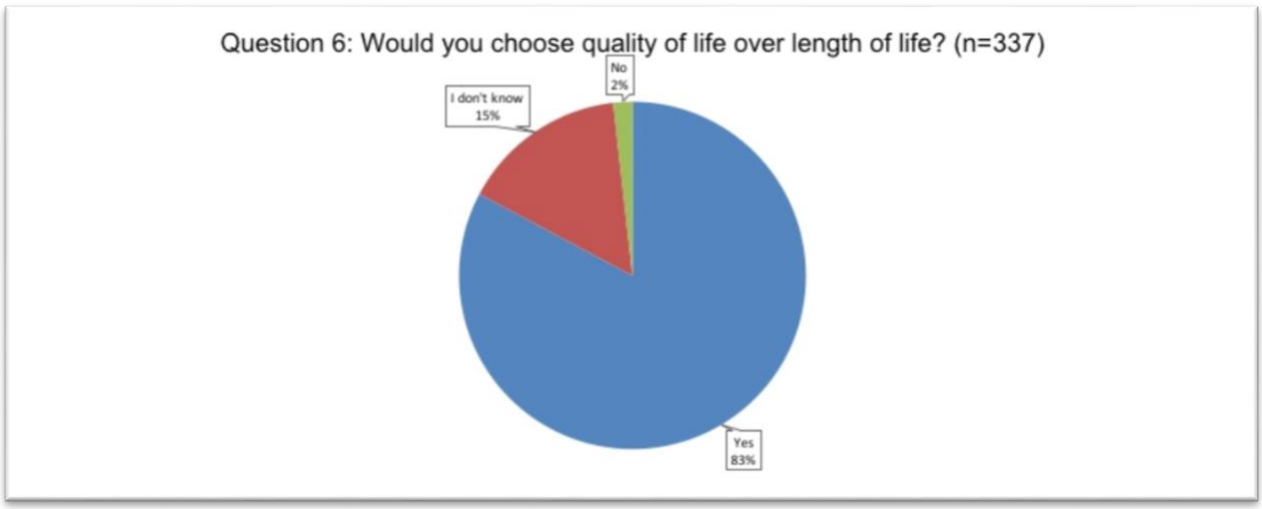
- *"Tough at any time to discuss, depends who the conversation is with"*
- *"A lot of people don't like to discuss it or make plans"*
- *"When my father was going through this journey our questions were answered by the head of palliative care as well as social workers & nurses."*
- *"Dying is a natural thing, should not be considered taboo."*



QUESTION 6: PRIORITIES OF CARE

Modern society, and in particular the health system, has a strong focus on lengthening life. This question aimed to question community members directly “would you choose quality of life over length of life?”

83% respondents would choose quality of life over length of life.

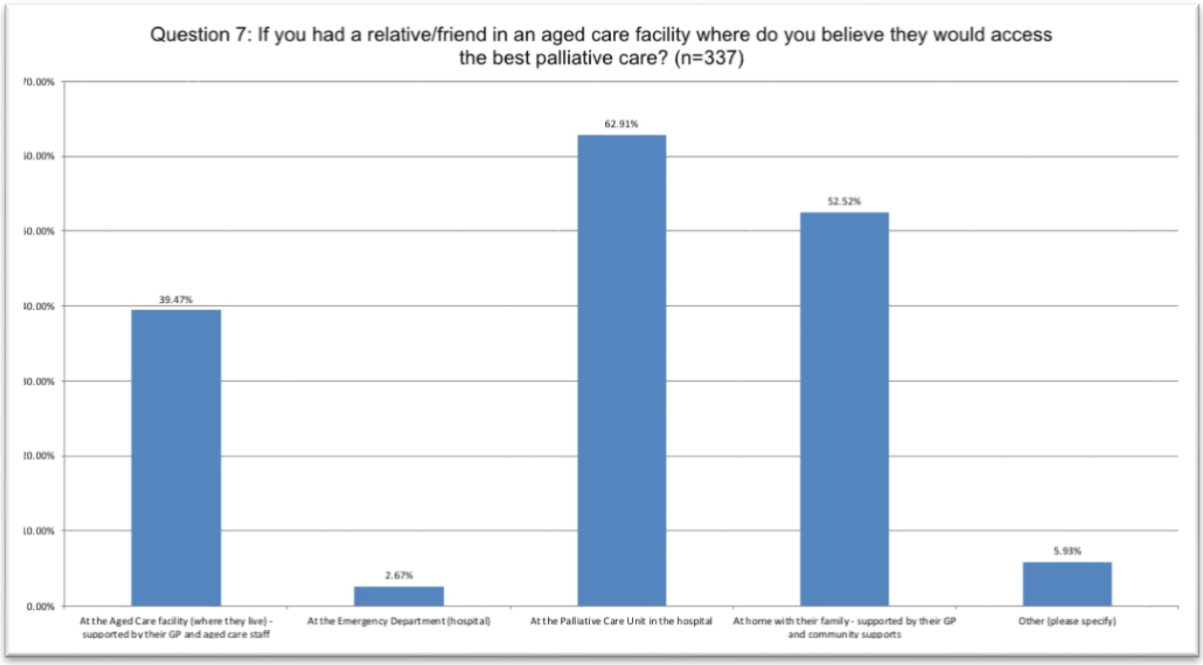


QUESTION 7: ACCESS TO PALLIATIVE CARE

This question aimed to gain an insight into where the community perceived 'best practice' palliative care to be located.

There was not a huge variance in the responses between Palliative Care Unit, Home or an Aged Care Facility. A very low number of respondents identified that the emergency department was the best location for palliative care.
Further comments included:

- *"a facility where family can live with the patient"*
- *"would depend on what support available and patient/family's choice"*
- *"…would depend on the situation…hospice my preference"*
- *"it should be where-ever they want to be"*
- *"It's personal choice. Where the person nominated. My friends Dad wanted to die at home but was made to go to Hospital because he hadn't pre-arranged his Palliative care."*
- *"They would probably get the "best" care in a PC unit but most would prefer to be home."*
- *"I do not believe Aged Care facility staff know how to make end of life as beautiful and comfortable as it should. All staff need more education including carer's."*



GREY FEEDBACK – COMMENTS FROM SOCIAL MEDIA

In addition to the direct survey responses we were surprised at the engagement of social media with comments and feedback.

Comments and feedback received on social media provided insights into community discussions, knowledge, awareness and how services could improve the care of patients at end of life. This rare insight has been described as 'grey feedback' because it is not formal feedback yet provides quality improvement data.

Grey feedback is rarely collected by health services and can be seen as a high-risk method of data collection due to the lack of control. However, during this survey, it was seen as a useful insight into existing community conversations that health providers are rarely privy to hear.

Grey Feedback collected throughout the Survey

Over 50 comments were collected via Facebook through public commenting or the private messenger function.

Several people described their disappointment with services and support for their loved ones at end of life, particularly in the acute care setting – many of these experiences were Australia wide and did not reflect an individual service.
Other people expressed their good memories and gratitude for services received at end of life. Key themes are shared below.

IMPROVING CARE AT END OF LIFE

Responses to the question generated some positive and negative feedback from some community members.
Overall negative responses indicated that health professional's explanations and approach to end of life care were not always understood by community members.

Issues surrounding satisfaction with the management of symptoms at end of life, not having enough time with loved ones at the end, poor communication with families and loved ones resulting in limited time they had to say goodbye to loved ones, use of medications to manage symptoms and having time to say goodbye.

Some unidentified direct quotes are shared below in themes:

Communication with patients and families regarding symptom management

"Don't over-medicate them when they are dying. Families want to be able to say their goodbyes to their love one while they are at least awake and can hear them. My father was so over medicated he never woke up from the minute he arrived in their care and they put a line in for direct medication. That was that. He died, and we never got to say goodbye even though we were there for hours on end waiting and hoping he would wake up!"

"Maybe listen to the person that's gunna die"

"Have a bit more compassion for both the one who is dying and the families"

"By having honest and open conversations with families"

Awareness of what to expect | Family as advocates

"It is hard when you have never been through this so have no idea what is acceptable care and what is not. I am sorry for everyone who has had a bad experience there. I too am haunted by our families experience of my father passing there. Now I feel some of our questions were warranted and now it is upsetting that we feel we were not strong enough advocates because we 'did not know how the system worked in their favour"

Positive Experiences | Good Memories

"I cannot fault the palliative care staff …. They took the very best care of my late husband…Even right down to the kitchen staff and the social worker …. They rescued us in our time of need and made sure he was as comfortable as could be at the end of his life. In my eyes they are all earth angels."

"I could not fault the staff nursing or doctors they were the most compassionate caring people to my family and my husband who was in palliative care. Nothing was too much for them to attend to for us and had many a joke with him and made him feel on top of it all. To me they are one of the wonderful people to work at the hospital. Not too many people can handle that part of nursing. My husband [sic] has been gone on just 15 months but I can still remember it all like yesterday and the beautiful people who helped us."

5. LIMITATIONS

Below is a summary of limitations identified with the survey process

Limited number of questions due to wanting to increase survey response rate *This likely limited PCQ being able to determine more detailed information about consumer experiences with palliative care and demographic information such as vulnerable groups, culturally and Linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) community in the survey*
Project was conducted as a Quality Improvement exercise, rather than a research project *This was due to the timeframe of the project deliverables. Without ethics the data was not able to be collected via the hospital*
Inability to collect the stories and experiences of palliative care – add an additional question for general comments *An additional question for general comments would allow respondents to share stories/experiences*
Additional option of ALL for Question 1 *This would have allowed people to identify that they agreed with more than one of the responses, and as more than 1 response is correct this would be an improvement to the question*
Ensure survey tool is easy to use and responses can be captured easily *A star tool was used for people to rate confidence - sometimes people were unable to apply accurately their responses and therefore placed them in comments*
Limited ability to understand how people access information or have conversations *People were asked confidence levels but it would be good to understand what they actually 'do' in response to accessing information and commencing conversations*

6. RECOMMENDATIONS

GENERAL RECOMMENDATIONS FROM THE RESULTS

The results of the Palliative Care Community Survey suggest that the Townsville community feel they have an understanding of palliative care, as well as both awareness and confidence in understanding how to access information and have conversations about palliative and end of life care.

Although it is a small sample size, with limited demographic variance, this challenges the commonly formed health professional assumption that health service priorities should be to increase confidence of community members to have conversation and sourcing information about palliative and end of life care.

It's recommended for health services in Townsville to consider shifting their priorities to include building on the existing levels of community confidence to source information and supports to ensuring the information and supports they source meet their needs.

An additional recommendation is to build on the existing community confidence to have conversations about palliative and end of life care to ensuring community members have confidence to initiate those conversations with health professionals as well.

In addition, this survey identified that the majority of people learn from experience and via their local connections, rather than health resources and websites. We recommend the community awareness campaigns need to include stories and experiences directly from local community members.

RECOMMENDATIONS FOR THE CONNECTING END OF LIFE CARE IN TOWNSVILLE PROJECT

As a result of this Palliative Care Community Survey the CELC-T project has identified 4 key improvements to be focused on:

1. Build community confidence to source palliative care information and services, to ensure the information they source is accurate and relevant to their needs.
2. Build on the community confidence in facilitating conversations about end of life to empower the community to initiate these conversations with health professionals.
3. Improve health professional's ability to explain the process of end of life care.
4. Share patient experiences and stories about end of life.

GENERAL RECOMMENDATIONS ABOUT THE SURVEY

The purpose of this community focused survey was to explore Townsville:

- Public knowledge about palliative care
- To gain an understanding about how the Townsville public are accessing and sharing information about palliative care
- Promote awareness of palliative care

With a response rate of 337 and a social media reach over 6,000 we believe that this survey achieved its stated goals.

APPENDIX 1: PALLIATIVE CARE COMMUNITY SURVEY

Have your say Townsville

Palliative Care Community Survey

Palliative Care Queensland is conducting the survey to promote education and awareness about palliative care. The following questions will be used to understand the general community's understanding and awareness of palliative care in Townsville.

The survey is entirely voluntary and will take approximately 5 minutes to complete. An incentive to complete the survey is a to win an IPAD MINI.
The personal information you provide to go into the draw for this prize will not be linked to your survey responses & your personal information will not be shared more widely than Palliative Care Queensland.

1. What does palliative care mean to you? (please tick a box)

- ☐ End of Life care
- ☐ Support to anyone with terminal diagnosis
- ☐ Better pain and symptom management
- ☐ Improved quality of life and death
- ☐ Don't know
- ☐ Other (please specify): _____

_____

2. How have you learned about palliative care ? (tick all that apply)

- ☐ Personal Experience
- ☐ Social Media (i.e. facebook, twitter etc)
- ☐ Print Media (i.e. articles in newspaper, brochures etc)
- ☐ Local Public Events
- ☐ Websites/Google/Videos
- ☐ Friends, family, co-workers, neighbours etc
- ☐ Other (please specify):

_____

3. How would you rate your knowledge about palliative Care? (please tick a box)

- ☐ Very good
- ☐ Good
- ☐ Poor

4. How confident do you feel about accessing information and supports about palliative care or end of life issues? (please tick a box)

☐ Very confident ☐ Reasonably confident ☐ Not very confident ☐ I don't know

Comments (optional): _____

5. How confident do you feel about having conversations about palliative care and the end of life? (please tick a box)

☐ Very confident ☐ Reasonably confident ☐ Not very confident ☐ I don't know

Comments (optional): _____

6. Would you choose quality of life over length of life? (please tick a box)

☐ Yes ☐ I don't know ☐ No

7. If you had a relative/friend in an aged care facility where do you believe they would access the best palliative care? (you can tick more than one answer)

- ☐ At the Aged Care facility (where they live) - supported by their GP and aged care staff
- ☐ At the Emergency Department (hospital)
- ☐ At the Palliative Care Unit in the hospital
- ☐ At home with their family - supported by their GP and community supports
- ☐ Other (please specify):

Almost there - we just have a few general questions now

Please place in the palliative care survey box when completed OR post to PCQ, PO Box 418, The Gap, Qld, 4061 Page 1 of 2

Have your say Townsville

Palliative Care Community Survey

8. Postcode where you live: _____

9. How do you identify your gender? (please tick a box)
☐ Female ☐ Male ☐ Other (please specify): _____

10. Which age range do you represent? (please tick a box)
☐ 18 to 24 ☐ 25 to 34 ☐ 35 to 44 ☐ 45 to 54
☐ 55 to 64 ☐ 65 to 74 ☐ 75 or older

OPTIONAL:
If you would like to go in the draw to win an Ipad Mini
(prize drawn 12th April 2018 terms and conditions are on our website: www.palliativecareqld.org.au/celc), please complete your details below.

11.
Name: _____

Email Address: _____

Phone Number: _____

12. Are you happy if Palliative Care Queensland contact you once in late 2018 to ask you to complete a similar community survey? (please tick a box)
☐ Yes
☐ No
☐ Other (please specify): _____

13. Would you like us to sign you up for the Palliative Care Qld free monthly e-news? (please tick a box)
☐ Yes
☐ No
☐ Other (please specify): _____

Palliative Care Queensland would like to thank you for your time.
We understand that time is precious, and life is busy so appreciate you sharing your views, experiences, and awareness with us.

For more information about Palliative Care Queensland (PCQ)
visit our website - www.palliativecareqld.org.au or phone 1800 660 055
To become more involved consider becoming a community member of PCQ (only $15/year)

Townsville CELC
CONNECTING END OF LIFE CARE

THE PALLIATIVE CARE COMMUNITY SURVEY IS PART OF THE CONNECTING END OF LIFE CARE IN TOWNSVILLE PROJECT - WWW.PALLIATIVECAREQLD.ORG.AU/CELC

PalliativeCare

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This project is supported by funding from the Australian Government under the PHN Program

Please place in the palliative care **survey box** when completed OR post to PCQ, PO Box 418, The Gap, Qld, 4061 Page 2 of 2