

Results of an on-line survey and telephone interviews

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## Introduction

Over 160,000 people live in Australian residential aged care facilities. Many of these residents will not only live in these facilities and see it as their home but will die there as well. Supporting and caring for residents includes enabling them to live well at the end of life and to die with dignity.

A new on-line resource, the RAC [HUB] was developed as part of the CareSearch website to provide palliative care information for aged care residents and for staff working in residential aged care. CareSearch is funded by the Australian Department of Health. It provides health professionals and patients (and residents), their carers, families and friends with access to evidence-based palliative care information and quality resources.

## What's the RAC [hub]?

The RAC [HUB] comprises a set of pages and online resources that have been assessed for their relevance and quality specifically developed to meet the palliative care information needs of residents and staff in residential aged care. Pages included in the [HUB] look at:

- People who work in residential aged care and their role and contribution to providing end of life care for residents
- Care issues including symptoms, recognising dying, and care planning
- Recognising the resident's needs
- Facility and quality issues and considerations
- Communication, spirituality and grief and loss
- Information for residents and their families.

Access to, and use of, evidence is made easier by a special literature searching tool that enables one click searches for articles in PubMed. This is a free to use biomedical library. There is an option to look only for whole articles that can be read for free. This makes it easy to find literature to read immediately. This literature search tool is called the RAC Search Filter and has instructions for use in the RAC [HUB].

A quarterly newsletter from the RAC [HUB] reports on new initiatives in the sector and new resources and content in the RAC [HUB]. Each newsletter includes a case study about a resident that highlights what needs to be considered and what resources and information are available to help in providing quality end of life care. Anyone can register to receive this newsletter for free.

The RAC [HUB] was launched in October 2012.

## **Methodology**

The RAC [HUB] was assessed by:

- (1) An on-line survey of RAC [HUB] users
- (2) Telephone interviews with key palliative care stakeholders.

Ethical approval was received from the Behavioural and Social Sciences Ethical Review Committee at the University of Queensland.

## **On-line survey**

The survey was based on a previous instrument developed by the University of Wollongong and CareSearch to evaluate the Nurses [HUB] in 2011. In general the objectives of these questions were to test the impact and effectiveness of the web pages. More specifically the questions aimed to:

- Identify what information would be useful to improve palliative care
- To gain an understanding on how the site was utilised
- To identify potential areas for improvement.

The final survey (See Appendix 1) included 31 questions and takes approximately 10 minutes to complete. Participants were asked to read a participant information sheet and indicate consent prior to completing the survey on-line (see Appendix 3).

Invitations to participate in the survey were sent out to approximately 797 individuals subscribed to the RAC [HUB] newsletter in August 2013. In addition, information about the survey and a link to the survey were included in other CareSearch newsletters. Two reminder emails were set out two weeks apart.

## **Telephone interviews**

Interview questions were based on the script developed by the University of Wollongong and CareSearch to evaluate the Nurses [HUB] (see Appendix 2). The key aim of the telephone interviews was to discuss how the RAC [HUB] could best support the information needs of residential aged care stakeholders and to gain further insight into how the resource could be improved. Interviews were conducted by telephone with experts in aged care management, clinical care, aged or palliative care, policy, leadership or education. The interviewees were chosen by the research team in consultation with Caresearch.

CareSearch sent out emails inviting 21 individuals to participate in a 30 minute interview as part of a quality improvement exercise. Six accepted the invitation, a further two nominated others from within their organisation or service. Two formally declined. The potential

participants were then contacted by a member of the research team to arrange a mutually convenient time to hold the telephone interview. When a participant agreed to be interviewed they were emailed a copy of the questions together with a participant information sheet and consent form (see Appendix 4).

## **Data analysis**

On-line survey data descriptives are reported. Comparisons between the residential aged care and non-residential aged care participants were made using Fisher's Exact Test.

All telephone interviews were tape recorded and transcribed verbatim. Each transcript was read by three members of the research team. As the interviews were semi-structured the analysis is reported by interview question. Common themes were identified for each question by a research team member. These themes were checked by the second and third member of the research team to ensure consistency. Quotes are provided to illustrate the answers to the questions.

## **On-line Survey Results**

A total of 115 responses were received to the on-line survey.

## **Participant characteristics**

## **Currently working in Residential Aged Care**

There were 106 responses to this question. The majority of respondents worked in residential aged care (RAC) (N=74, 69.8%) (Figure 1).

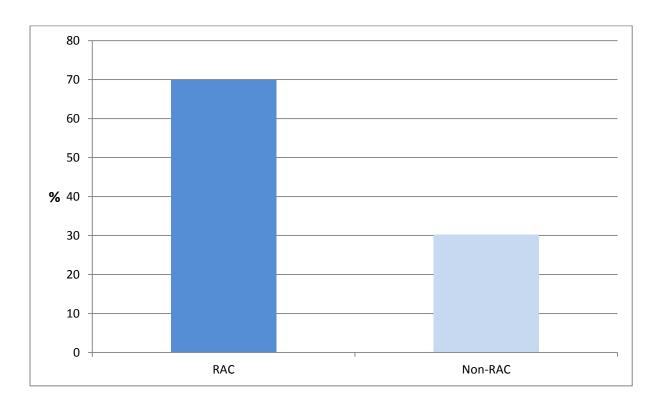


Figure 1: Percentage of respondents currently working in Residential Aged Care

#### **Age Group**

114 respondents answered this question. Almost 60% of respondents (N=68, 59.6%) were aged 50 years or over. Although not statistically significant, the RAC group were more likely than the non-RAC group to have participants aged 50 years or over (64.9% v 48.4%, p=0.13) (Figure 2).

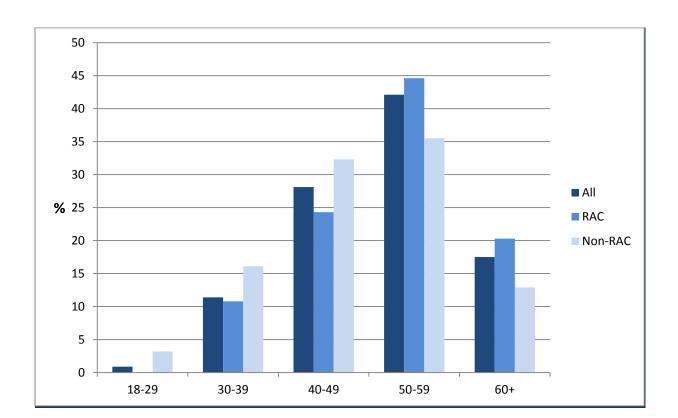


Figure 2: Percentage of respondents by age group for All, RAC and Non-RAC

### **Postcode**

To accurately determine the geographic spread of respondents a geographic classification system which categories areas using postcode was utilised - namely, the Australian Standard Geographical Classification (ASGC). This classification divides Australia into six broad regions called Remoteness Areas (RAs): very remote, remote, outer regional, migratory, major cities, inner regional.

Australian postcodes were reported by 108 respondents. Over half (57.4%) of the respondents worked in major cities. Figure 3 displays the geographic spread of respondents based on their ASGC classification. There was a non-significant trend indicating that RAC respondents were less likely than non-RAC respondents to work in major cities (55.6% v 65.5%, p=0.38) (Figure 3).

Postcode data also allowed identification of the state in which the respondents primary job was located. Respondents were most likely to work in Victoria, New South Wales or Queensland (see Figure 4).

Two respondents indicated they worked in Singapore.

Figure 3: Percentage of respondents by AGSC classification for All, RAC and Non-RAC

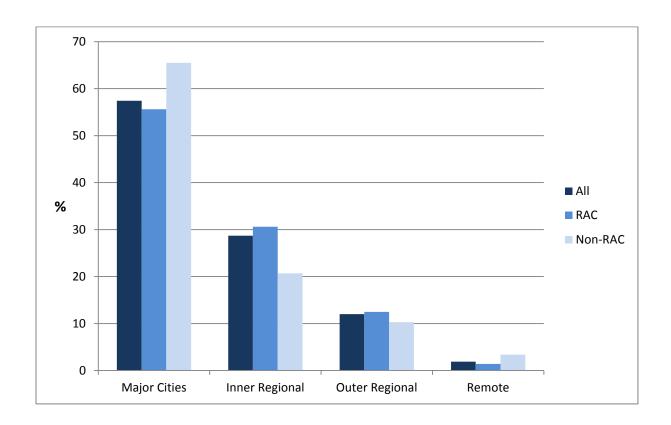
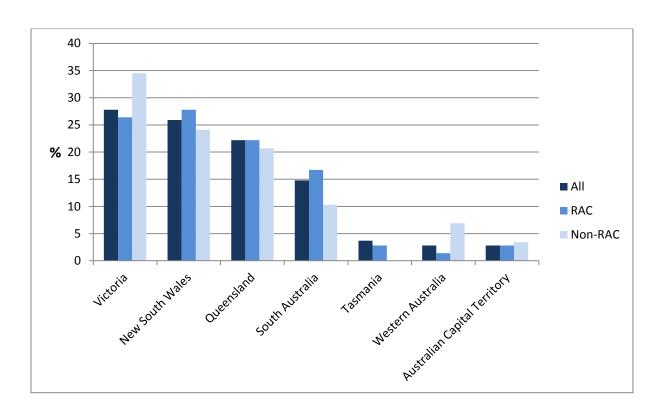


Figure 4: Percentage of respondents by state for All, RAC and Non-RAC



## Main role in primary workplace

All respondents reported their main role in their primary workplace. Management and registered nurses were the most likely to participate in this survey. "Other" respondents included: an administration officer, a retired RAC nurse and a person working in community service (not otherwise specified) (Table 1).

Table 1: Main role in primary workplace

Role	All	RAC	Non-RAC
	N (%)	N (%)	N (%)
Care Director/ Director of Nursing/ Manager	27 (23.5)	21 (28.4)	4 (12.5)
Registered nurse	27 (23.5)	17 (23.0)	8 (25.0)
Clinical nurse specialist	12 (10.4)	8 (10.8)	2 (6.3)
Educator	11 (9.6)	6 (8.1)	4 (12.5)
Personal care worker	7 (6.1)	6 (8.1)	1 (3.1)
Nurse unit manager	6 (5.2)	5 (6.8)	1 (3.1)
Enrolled nurse	4 (3.5)	4 (5.4)	-
Allied health	4 (3.5)	1 (1.4)	3 (9.4)
Quality control	4 (3.5)	3 (4.1)	-
Pastoral care	3 (2.6)	-	3 (9.4)
Student nurse	2 (1.7)	-	2 (6.3)
Project officer	2 (1.7)	1 (1.4)	1 (3.1)
Nurse practitioner	1 (0.9)	-	-
Diversional therapist	1 (0.9)	1 (1.4)	-
Researcher/ Academic	1 (0.9)	-	1 (3.1)
Other	3 (2.6)	1 (1.4)	2 (6.3)

## **Access Specialist Palliative Care Services**

This question was only asked of respondents working in residential aged care – 71 responses were received. Almost 80% of respondents indicated they accessed support from specialist palliative care services (see Figure 5).

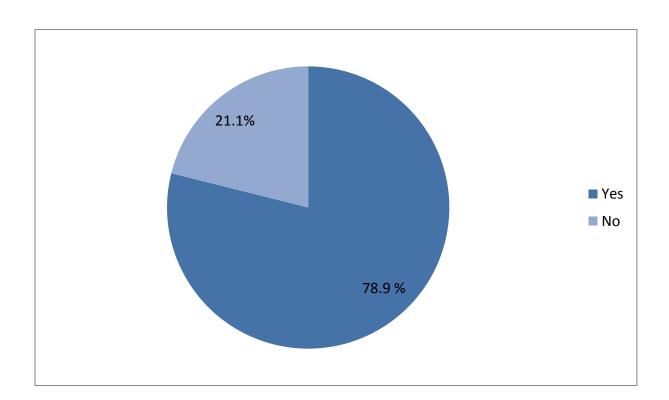


Figure 5: Percentage of respondents accessing support from specialist palliative care services

### **Current palliative care initiatives**

The most common initiatives related to education, and development of policy documents and guidelines (see Table 2). Although advance care planning, family meetings and end of life care pathways were utilised by approximately 70-75% of respondents.

"Other" initiatives included: specified education (attending seminars, viewing Aged Care Channel, ongoing study and on-line learning); networking and developing relationships with specialist providers and GPs; specialist referrals; nursing consultation, assessment and care planning; utilising palliative care champions/ working groups; conducting focus groups with staff, allied health and residents; providing an environment conducive to palliative care.

Table 2: Current palliative care initiatives in residential aged care

Initiative	N (%)
Education	64 (86.5)
Policy documents/ guidelines	60 (81.1)
Advance care planning	56 (75.7)
Family meetings/ case conferences	56 (75.7)
End of life care pathway	51 (68.9)
Other	13 (17.6)

## **Survey questions**

### Are you aware that CareSearch has a RAC [HUB]?

There were 115 responses to this question. Approximately 70% of respondents indicated they were aware of the RAC [HUB] (N=81, 70.4%). Although people working in residential aged care were more likely to be aware of CareSearch's RAC [HUB] than those not working in residential aged care, the difference was not statistically significant (73.0% v 65.6%, p=0.49) (Figure 6).

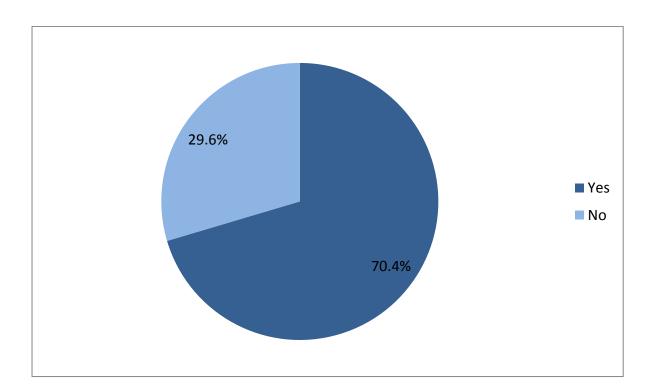


Figure 6: Percentage of respondents aware of Caresearch's RAC [Hub]

#### How did you find out about the RAC [HUB]?

There were 81 responses to this question. The most common way of finding out about the RAC [HUB] was through promotional materials and newsletters or publications for RAC and non-RAC respondents, respectively (Table 3).

Table 3: Most commonly reported awareness raising strategies

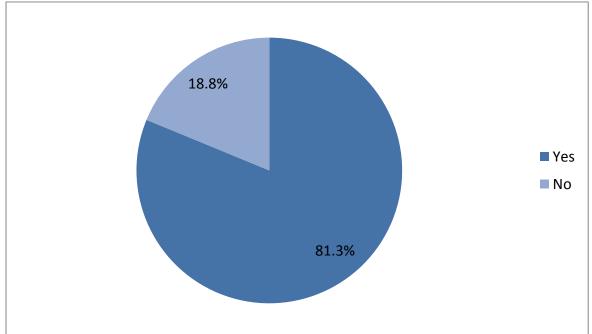
Awareness raising method	All	RAC	Non-RAC
	N (%)	N (%)	N (%)
Promotional materials	28 (34.6)	21 (38.9)	5 (23.8)
Newsletters or publication	23 (28.4)	13 (24.1)	7 (33.3)
Recommended by a colleague	17 (21.0)	10 (18.5)	6 (28.6)
Conference or presentation	13 (16.0)	9 (16.7)	2 (14.3)
Internet search	8 (9.9)	5 (9.3)	2 (9.5)
Not sure	9 (11.1)	5 (9.3)	3 (14.3)

<sup>&</sup>quot;Other" ways of finding out about the RAC [HUB] included: emails (N=2, 1.7%), Flinders University (N=1, 0.9%), and searching the CareSearch website (N=1, 0.9%).

## Have you visited the RAC [HUB]?

Eighty of 81 participants responded to this question. Over 80% (n=65, 81.3%) had visited the RAC [HUB]. There was no difference between RAC and non-RAC groups (79.6% v 81.0%, p=1.0) (Figure 7).

Figure 7: Percentage of respondents visiting the RAC [HUB]



Of the 15 respondents indicating that they had not visited the RAC [HUB], the most common reasons were: having only just heard about it (N=8, 53.3) and not having the time (N=6, 40.0%). No "other" responses were offered (Figure 8).

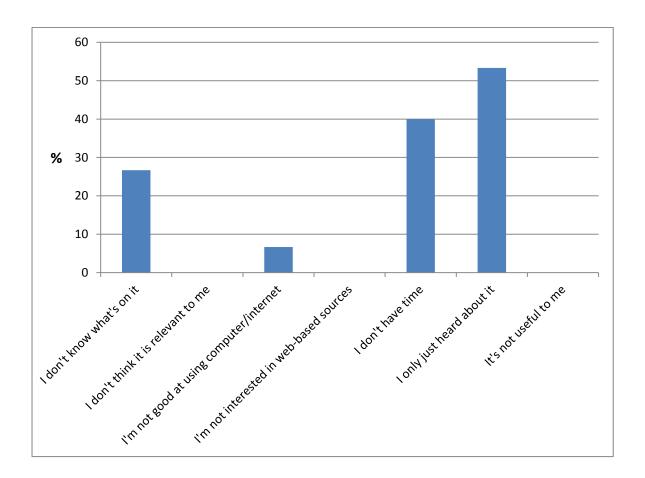


Figure 8: Reasons for not visiting RAC [Hub]

### What would you encourage you to use it?

Seven of the 15 respondents indicating that they had not visited the RAC [HUB] answered this question. Three respondents indicated time was an issue: "maybe I can try to use it now, I need to give myself time for it"; "more spare time". Two respondents indicated informational prompts would be motivating: "email prompts of interesting things that may be on it so as you can just press on the link on the email – this would definitely be handy"; "more info[rmation] sent to me about the site". One respondent indicated specific content would attract him/her to the site: "evidence based research in dementia, palliative care and care for CALD resident". Another respondent indicated that information that "would assist in my role at work" would be a motivator.

### Approximately how often do you visit the RAC [HUB]?

All participants asked this question responded (N=65). Over 50% of respondents (N=35, 53.8%) indicated they visited the RAC [HUB] at least once a month. Although the RAC group were more likely than the non-RAC group to visit the RAC [HUB] at least once a month, the difference was not statistically significant (58.1% v 41.2%, p=0.26) (Figure 9).

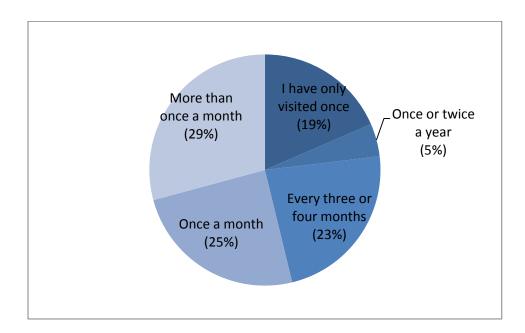


Figure 9: Frequency of visits to RAC [Hub]

#### Is the format of the RAC [HUB] easy to navigate?

Of the 65 respondents answering this question, most respondents (N=41, 63.1%) indicated that the RAC [HUB] was "somewhat easy" to navigate (Figure 10).

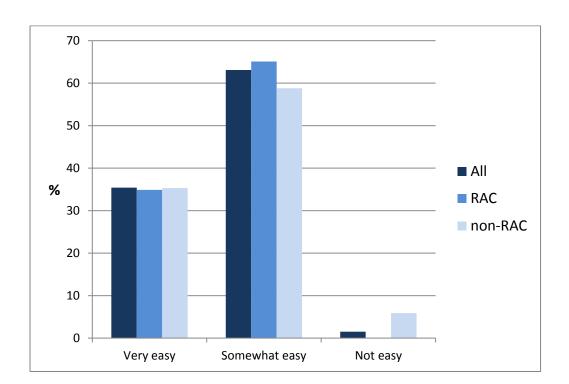


Figure 10: Ease of navigation for All, RAC, Non-RAC

## Which section of the RAC [HUB] have you visited and how useful was each of the sections?

This question was asked of 65 respondents. Table 4 lists the percentage of respondents visiting each section.

Table 4: Percentage of respondents visiting each section of the RAC [HUB]

Section	All	RAC	Non-RAC
	N (%)	N (%)	N (%)
Care issues	60/62 (96.8)	38/40 (95.0)	17/17 (100.0)
Literature and resources	55/61 (90.2)	37/41 (90.2)	16/16 (100.0)
Recognising residents' needs	51/59 (86.4)	32/39 (82.1)	14/15 (93.3)
What's new in RAC	48/59 (81.4)	34/39 (87.2)	10/15 (66.7)
Communication	48/59 (81.4)	30/39 (76.9)	14/15 (93.3)
People working in RAC	43/54 (79.6)	29/36 (80.6)	10/13 (76.9)
Facility/quality issues	45/59 (76.3)	30/40 (75.0)	12/14 (85.7)
For residents and families	38/54 (70.4)	21/35 (60.0)	13/14 (92.9)

The most commonly visited sections in both groups were "care issues" and "literature and resources". The least commonly visited section by RAC and non-RAC groups were "for residents and families" and "what's new in RAC", respectively.

Table 5 lists the percentage of respondents reporting a section was "very useful".

Table 5: Percentage of respondents finding section of RAC [HUB] "very useful"

Section	All N (%)	RAC N (%)	Non-RAC N (%)
Care issues	34/60 (56.7)	21/38 (55.3)	11/17 (64.7)
Literature and resources	27/55 (49.1)	19/37 (51.4)	8/16 (50.0)
Recognising residents' needs	24/51 (47.1)	16/32 (50.0)	7/14 (50.0)
What's new in RAC	21/48 (43.8)	13/34 (38.2)	7/10 (70.0)
For residents and families	15/38 (39.5)	8/21 (38.1)	6/13 (46.2)
People working in RAC	15/43 (34.9)	10/29 (34.5)	4/10 (40.0)
Communication	16/48 (33.3)	10/30 (33.3)	5/14 (35.7)
Facility/quality issues	13/44 (28.9)	8/30 (26.7)	5/12 (41.7)

RAC and non-RAC respondents were most like to nominate the "care issues" and "what's new in RAC" as "very useful", respectively. The "facility/quality issues" and "communication" sections were least likely to be nominated as "very useful" by the RAC and non-RAC groups, respectively. In each of the following sections ("people working in RAC", "family/quality issues", "literature and resources" and "what's new in RAC") one participant indicated that they found the content "not useful".

# Are you aware of the RAC [HUB] newsletter? Are you registered to receive the RAC [HUB] newsletter?

Of the 65 respondents asked this question, almost 90% were aware of the RAC [HUB] newsletter (N=57, 87.7%). There was no statistically significant difference between the RAC and non-RAC groups (93.0% v 88.2%, p=0.62). Eighty percent of respondents (N=52) were registered to receive the RAC [HUB] newsletter. Again there was no statistically significant difference between RAC and non-RAC groups (81.4% v 88.2%, p=0.71) (Figure 11 and 12).

Figure 11: Aware of RAC [Hub] newsletter

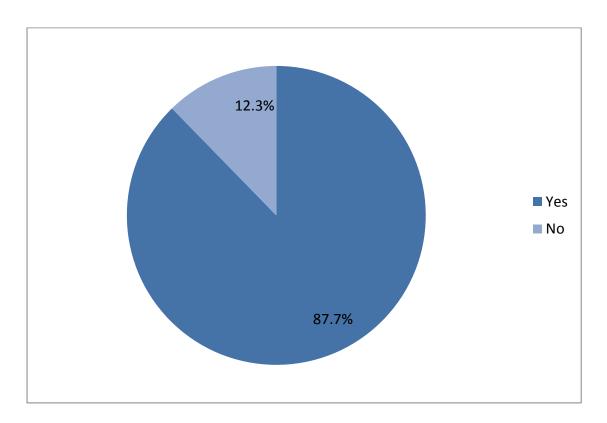
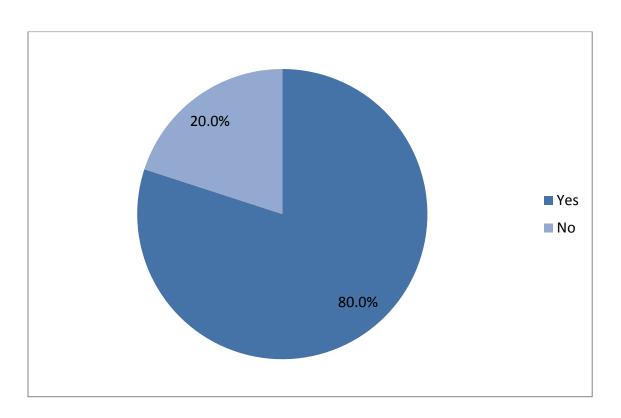


Figure 12: Registered to receive newsletter



## If you visited the RAC [HUB], have you used any of the information you found?

Of the 65 respondents asked this question over 70% (N=48, 73.8%) reported they had used the information they found on the RAC [HUB]. The RAC group did not differ significantly from the non-RAC group (76.7% v 70.6%, p=0.74) (Figure 13).

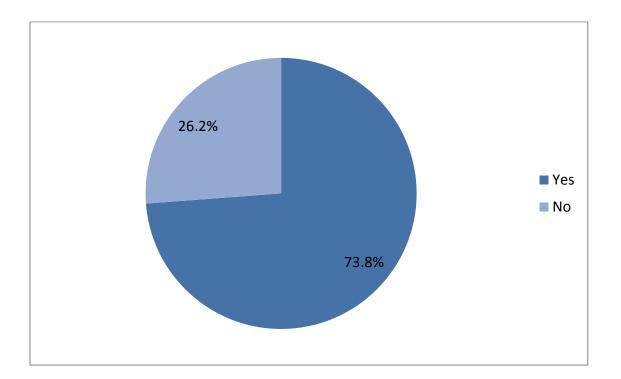


Figure 13: Have you used information from the RAC [Hub]?

## If you used the information, what was it for and was it useful?

This question was asked of 48 respondents. Overall, and for the RAC group, the most common uses for RAC [HUB] information included: personal development, discussions with other health professionals, and as a discussion point. The most common uses of information for the non-RAC group were: personal development, teaching others, discussions with other health professionals, and handouts. Both groups were least likely to use the information in newsletters (Table 6).

Table 6: Percentage of respondents utilising RAC [HUB] information for a specified reason

Use	All	RAC	Non-RAC
	N (%)	N (%)	N (%)
Own development	43/44 (97.7)	31/32 (96.9)	10/10 (100.0)
Discuss with another health professional	39/42 (92.8)	27/29 (93.1)	10/11 (90.9)
Discussion point	37/41 (90.3)	27/29 (93.1)	7/9 (77.8)
Disseminate to others	36/41 (87.8)	25/29 (86.2)	8/9 (88.9)
Support an idea or argument	35/40 (87.5)	25/28 (89.3)	7/9 (77.8)
Provide handouts	35/40 (87.5)	24/28 (85.7)	9/10 (90.0)
Teaching others	37/43 (86.1)	24/29 (82.8)	10/11 (90.9)
Change an area of practice	32/39 (82.0)	23/28 (82.1)	7/9 (77.8)
Discuss with a manager	30/39 (77.0)	20/27 (74.1)	8/10 (80.0)
Include in newsletters	25/35 (71.4)	17/24 (70.8)	6/9 (66.7)

Both groups were most likely to find the information "very useful" for: personal development and discussions with other health professionals. Both the RAC and non-RAC groups were less likely to find the information "very useful" for discussions with managers. Only one participant reported the information as "not useful as all" with reference to use in newsletters (Table 7).

Table 7: Percentage of respondents reporting the information "very useful" for a specified reason

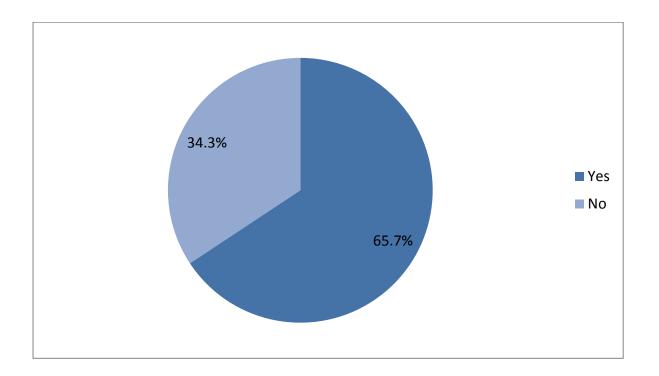
Use	All	RAC	Non-RAC
	N (%)	N (%)	N (%)
Own development	32/43 (74.4)	22/31 (71.0)	9/10 (90.0)
Discuss with another health professional	25/39 (64.1)	17/27 (63.0)	8/10 (80.0)
Teaching others	22/37 (59.5)	14/24 (58.3)	7/10 (70.0)
Provide handouts	20/35 (57.1)	13/24 (54.2)	7/9 (77.8)
Support an idea or argument	18/35 (51.4)	12/25 (48.0)	5/7 (71.4)
Disseminate to others	18/36 (50.0)	10/25 (40.0)	6/8 (75.0)
Change an area of practice	16/32 (50.0)	12/23 (52.2)	4/7 (57.1)
Discussion point	17/37 (45.9)	10/27 (37.0)	5/7 (71.4)
Discuss with a manager	12/30 (40.0)	7/20 (35.0)	5/8 (62.5)
Include in newsletters	10/25 (40.0)	7/17 (41.2)	3/6 (50.0)

Five participants reported the data useful for "other" reasons including: study (N=3), research (N=1), and to provide information to families (N=1). All four respondents who rated the usefulness of the information for "other" reasons rated it as "very useful".

Has the information in the RAC [HUB] assisted you to make any changes in palliative care practice within your service?

Of the 35 respondents who had both used information from the RAC [HUB] and worked in some form of palliative care service, 65.7% (N=23) stated they had used the information to make changes in palliative care practice (Figure 14).

Figure 14: Percentage utilising the information to make changes in palliative care practice within their service



## If yes, please give an example.

Practice changes related to four main themes (Table 8):

- Education of or discussion with staff or other health professionals; CareSearch was viewed as an information source with useful resources
- Education of or discussion with consumers including families of residents
- Organisational structures, policies and procedures
- Clinical practice with reference to evidence-based practice and use of clinical guidelines

Table 8: Examples of changes in palliative care practice

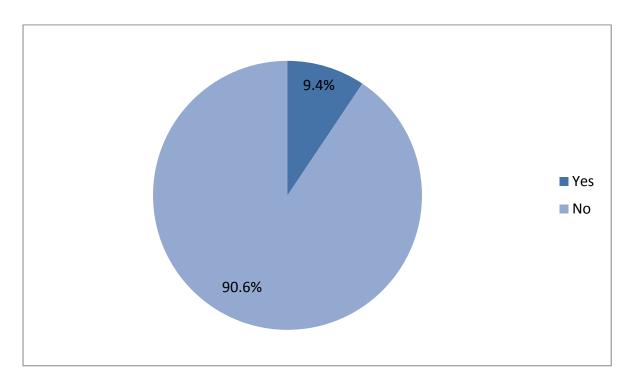
Figure 1	
Example	Quote
Education/ discussion	"Ability to provide relevant information to staff"
with staff/ other health	"Able to have discussion with colleagues [about] pros and
professionals; information	cons of sub cut fluids"
source; availability of on-	"Assisted in providing staff with knowledge base, towards
line resources	identifying a residents' requirement for palliative care, at an
	earlier stage of disease process, rather than only during last days of life"
	"Currently implementing new palliative care education
	initiatives in both our aged care and acute facility with a view
	to improving our palliative care knowledge and skills"
	"Discussing with GPs on better practice"
	"Disseminated the information to staff to improve knowledge"
	"Education to Residential Aged Care Facilities Staff as a
	resource for reliable informationto advise staff to sign up
	for the newsletter"
	"Helping staffto not be afraid of opioid use but also to assist
	staff with assessment protocols and management of care
	issues"
	"Informing staff of the resource that they can access"
	"Our Palliative care service promotes its use to support
	RACFs and GPs"
	"Direct care staff to on-line and other education
	coursesnewsletters and articles of interest are
	disseminated and discussed at meeting where there are
	topics of interest"
	"On-line training and awareness of resources available which
	assist in time saving in research/ implementation of training
	with view to improving quality of care/ end of life care"
	"The links to other useful quality resources in Australia and
	around the world are invaluableall of this has changed our
	focus and improved resident care"
Education/ discussion	"Ability to provide relevant information toconsumers"
with consumers/ families	"Communication with families and significant others"
	"For material to print for families, for an alternative to
	families 'googling' their own information that is often
	unreliable"
	"Helpingfamilies not to be afraid of opioid use"
	"The resources available have assisted to educate families"
	"Talking to families about current treatment options and
	death and dying"
	"It has also given me more confidence in my every day
	practice when talking to families about current treatment

	options and death and dying"
Organisational structures,	"Have a system in place, better communication with the
polices and procedures	team, improve the policy, improve ACP, improve palliative
	[imprest]"
	"Starting routine family conferencing when a change in
	condition is identified"
	"The information has supported organisations policy and
	procedures"
	"The site has encouraged us to align our [policy and
	procedures] with evidence-based practice"
	"Trying to get the ACP committee active againtrying to
	incorporate ACP in Stroke worktrying to make the palliation
	of some clients more client-centred"
Clinical procedures/	"Managing cytotoxic medications"
guidelines/ evidence-	"To be able to detect the early signs of when someone
based practice	should be deemed palliative"
	"We used the information to help us finalise a flow chart for
	more definitive identification of the dying stage"
	"Use Guidelines to Palliative Care to implement a palliative
	approach long before end-of-life care"
	"To promote evidence-based practice"

## Is there anything that you would change about the information and resources on the RAC [HUB]?

Of the 65 respondents asked this question, 64 responded. Of these 58 (90.6%) indicated they would not change anything (Figure 15).

Figure 15: Is there anything you would change about the information and resources on the RAC [Hub]?



## If yes, what changes would you make?

Four participants responded to this question. Three of these responses related to navigation issues:

- "Easier navigation to the resources"
- "It was easier for new staff to find the RAC hub when there was a red button to click, now it is harder for them to navigate to the hub"
- "Make the Palliative Approach Toolkit link very obvious"

One participant indicated that some information could be expanded:

"Some information has been very limited"

### Is there anything that you would like to see on the RAC [HUB]?

Of the 65 participants asked this question, 60 replied. Of these, nine (15.0%) answered in the affirmative (Figure 16).

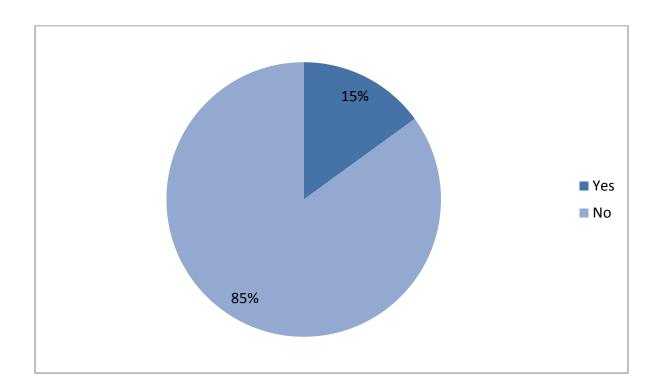


Figure 16: Is there anything you would like to see on the RAC [Hub]?

#### If yes, what would you like to see?

## Suggestions included:

- A chat room where issues could be raised
- Conference updates
- E learning package on managing cytotoxic medications specifically designed for RAC staff
- More Australian based content/ references
- More information on advance care directives applicable to Victorian legislation
- More information on documentation e.g., nursing care plans for a palliative resident
- More direction on where to locate content on the site

## Do you, or would you, recommend the RAC [HUB] to your colleagues?

Of the 65 respondents asked this question, 64 (98.5%) stated they would recommend the site (Figure 17).

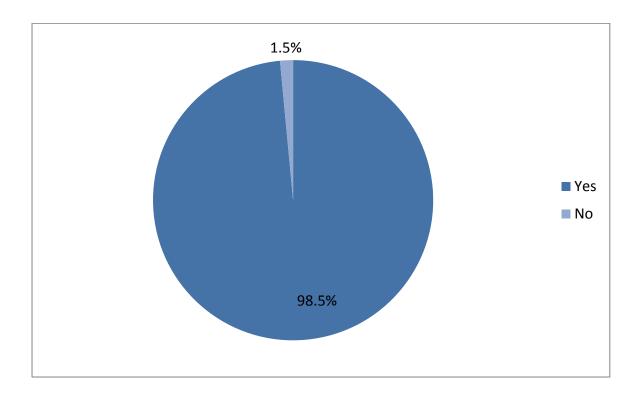


Figure 17: Would you recommend the RAC [Hub]?

Do you have any ideas on how to promote the RAC [HUB] or increase subscriptions to the RAC [HUB] Newsletter?

## Suggestions included:

- Mailouts to managers and staff at RACFs; asking to forward to peers/staff; newsletters to RACFs
- Advertisements in ACN Journal, Aged Care Journals, Connect
- Promotion through social media e.g., Facebook, Twitter
- Promotion at local events e.g., CAREX
- Promote within other stakeholder organisations e.g., Alzheimer's Australia, COTA
- Promote in student groups e.g. university/TAFE
- Rural/regional tours
- Link to CPD points for nurses
- Promote at conferences, senior functions/expos
- Links to HUB from state provider organisation websites
- Advertise in the ANF newsletters/website

- Educational flyers, promotional posters for RACFs
- Promote through ASCA
- Promote through MOA
- Send out information to doctors, hospitals

#### Do you have any suggestions for improving the RAC [HUB]?

#### Suggestions include:

- Better search engine
- More information on local resources
- Some learning modules
- Improved navigation to access HUB

#### Is there anything else that you would like to add a comment on?

Four general (and positive) comments were made: "All very comprehensive"; "I find site useful"; "This is a great resource"; "It is a wonderful site, fantastic".

Two respondents commented on the educational benefits:

- "I find the educational resources very useful and I have completed the online Palliative care training package."
- "The Hub has made my studies much easier to find information...thank you."

One respondent highlighted the benefits of having quick access to research:

"Great to have evidence-based research at your fingertips."

A final comment related to changing beliefs about palliative care and terminal care:

"Aged care staff need to grow in understanding that palliative and terminal care are
not synonymous. They provide excellent terminal care in my experience. There is,
however, a lack of appreciation of the social aspects of palliative care: the inclusion
of significant others in the journey of a person where medical cure is no longer
possible."

## Where do you usually access the RAC [HUB]?

Sixty-five participants answered this question. Respondents most commonly accessed the RAC [HUB] from work (N=34, 52.3%). Accessing from a mobile phone or library were the least common responses (Figure 18).

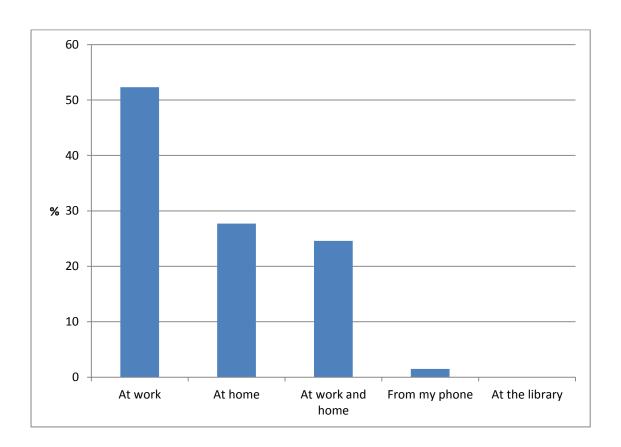


Figure 18: Where do you usually access the RAC [Hub]?

## **Telephone interviews**

## **Participants**

Interviews were conducted with nine participants (two participants were colleagues from the same organisation and were interviewed together). The state and territory representation is indicated in Table 9.

Table 9: State and territory representation of interviewees

State or Territory	Number
Queensland	2
New South Wales	1
ACT	1
Victoria	1
Western Australia	2
South Australia	2

## **Interview Questions**

### Current role and relationship to residential aged care

The interviewees held a range of roles: some worked directly in the residential aged care (RAC) sector, others worked in palliative care or for industry peak bodies. In summary, the roles included:

- Senior national positions in peak lobby organisations
- A Palliative Care Nurse Practitioner
- Leadership, clinical and education positions in RACFs
- A Research Fellow and educator for a peak lobby organisation
- A Government project officer

#### Awareness of, and thoughts about, the RAC [HUB] in CareSearch

Interviewees reported they were made aware of the RAC [HUB] in CareSearch through a variety of mechanisms that included:

- Care providers
- Colleagues
- Search engines like Google
- Links to CareSearch on their service's intranet
- Email reminders from newsletters or mailing lists

Some positive thoughts about the RAC [HUB] in CareSearch included:

- The hub was user friendly
- The site used plain English and was easy to search
- The inclusion of overseas materials provided linkages to more resources outside of Australia

One suggestion on improving exposure is to provide the RAC [HUB] newsletter in PDF format. This allows organisations to load it onto their intranet and therefore access to the internet is not required by all staff which can be a barrier. A PDF can also be used as an attachment via the organisations internal email alert system. It was felt by this participant that this may increase uptake and exposure of the RAC [HUB]. The online learning modules were seen as very useful but there was some issue with IT for nurses to be able to access these from one organisation. The following comments provide an overview of participants' views on the RAC [HUB].

"I mean it's certainly very user friendly. It's plain English...and it's easy to search it... simply from ease of access, the information's there."

"I like the fact that you've got, in most of the topic choices, you've got multiple resources, or linkages to multiple other resources."

"It's a unique resource. I've really never come across anything like this anywhere else that distils, and to some extent, facilitates access to the latest and the highest impact."

"I think it's fantastic. I think ...if you're working in residential aged care, and you needed some clinical or social information, it's a fantastic resource, and certainly a great place to start. And the information leads onto other things, if you want to go to other areas, it's there, it quides you."

Ways the RAC [HUB] can provide evidence about end of life care that would assist people working in residential aged care

Ways that the RAC [HUB] is seen as providing evidence about end of life care include:

- The information can be printed off and displayed on noticeboards, or taken to meetings
- The use of search filters makes information more accessible
- That it includes links to locally relevant sites
- That it can be used to promote best practice information to GPs, so they are on the same page as nurses
- The information can be used to assist with the development of policies and guidelines within the organisation

One participant indicated that while it looked daunting you could navigate easily and it could be suitable for consumers as well as health professionals:

"When I first looked at it I thought perhaps it was a little bit complex; but really when you spend time over it it's fairly self-explanatory so if you were a consumer or if you are a carer or a manager or a leader within the aged care environment or if you're in the community it fairly easily leads you to where you need get the information from. So I thought that it was very useful."

Another felt there was real value when providing education to their staff to highlight that the resource existed so that they could become users when they needed to find information.

"It's important for them to know that there is such a thing as the RAC [HUB] or CareSearch and website and so get them used to using it or being informed that there is such a site so that if they had the opportunity to let others know they can and also be able to use it themselves."

## Most significant barriers for people working in residential aged care with respect to using online resources

#### Barriers were identified as:

- Finding time between clinical care to sit at the computer
- Lack of access to a computer
- Lack of access to the internet
- Poor remote/offsite access to online resources
- Preference to receive information in hard copy
- Lack of confidence with using a computer
- Insufficient training for staff to use computers in research and continuing education, not just for clinical purposes
- Knowing where to look information up on the web
- Inadequate IT systems

#### Comments reflect these issues:

"Well, I think probably the biggest one is actual time to do so in between actual resident care and all the thousands of tasks people have to do, actually finding time to sit down at the computer is probably the biggest barrier. Access to the computers is, as I understand it, is quite a big barrier for people in residential care facilities."

"Most of the people read most things but people come directly to us for hard copy information quite a lot and that's probably still the preferred."

"... best practice guides for residential care and at a facility level, people actually prefer to have these things in hard copies that people can look at."

"I think most people these days do have access to a computer; there's a confidence issue, very little training around the computer. They will use it for everyday work that they have to enter electronically, but then they don't go beyond that and use it as a tool for learning. So that's still a barrier. I think that a lot of staff in residential aged care still don't use what's on there for professional learning."

"Again, it comes down to the capability, the IT capability of the organisation. I was recently at one of our external facilities and it took me, probably, twenty minutes to be able to open up the terminal, log onto the system, because I was doing it remotely and I thought 'you know, no wonder they don't bother'."

"I think it's basically knowing where to go rather than just doing a Wikipedia search. And I think that those shorthand...even a sign about where do you go to look for this information and just the website."

"A lot of staff do have their desk computers but can't access the internet, so they'll open ...they can access the electronic database at the facility, for resident information. They can't access anything else. Most of them won't have access to email, they just use it for daily resident care."

### Perceived best ways of addressing barriers

Strategies for addressing barriers to online information were identified as:

- Greater provision of computers/laptops
- Allowing staff education time
- Reminding staff of available online resources
- Providing facility for staff to leave feedback about online resources
- Posting links from the RAC [HUB] on the RACFs intranet

Some comments provided by participants indicate they want to encourage use of IT by staff:

"We're just at the moment setting up a new facility that's going to be opened in a couple of weeks... The reason why the staff has asked for laptops is because they're now going to be doing the documentation on the computer at the bedside, not on paper. So while you're interviewing somebody or discussing their care or doing their assessment you are in their room doing it as you chat to them, not doubling up. So that's the request that I've had and we're already trialling it at a couple of sites using the laptops and it seems to be working well."

"I think just continually informing the facilities that this resource is available. You've got the aged care website, and the aged care channel and other electronic sources that the facilities use for their education. I think if you had a really good clinical coordinator, she might be someone who would steer people towards this and then perhaps during education sessions, they could go into Care Search and then into the RAC hub and talk people through...what they can actually access through there."

"We had it as a link on one of our internet pages, directly through to Care Search, and you know we tried to encourage our staff to use it as well. So anybody who logs onto the intranet and has an email account, which is the bulk of our professional staff and quite a few of our nursing staff, on our clinical care page under useful links, they can click on the Care Search link and it will take them to Care Search and the RAC hub."

However, not all indicated that online was the best option:

"Not all the nurses have email access, so therein lies your issues about who the information becomes available to. If it's on a PDF version, every staff member... irrespective of who they are has access to the intranet. Any document we load on there, everybody can use it and my interest in that is care workers who really are student nurses working as care workers, there is my source of...giving, putting information, putting evidence, putting articles there, so they can access it without needing an email account so why deprive them of the information if I can give it to them in a format that they can easily access. That's why PDF documents work well for me. So the key for me is to access the information from the RAC hub, send me the PDF, send us the link but also in PDF format."

## Perceived challenges posed by providing end of life care for providers of residential aged care in the future

Barriers to providing end of life in RACFs were identified as:

- Low motivation/ambitions of RNs in aged care
- Maintaining/providing staff training regarding palliative care
- Access to equipment e.g. syringe drivers
- Being 'on the same page' as GPs
- Families not having end of life discussions
- Shorter length of resident stay

- Staff needing to be emotionally prepared to discuss end of life with families
- Baby boomers seen as more demanding regarding care of their family members
- Possible increased preference to be nursed at home, if RACF fees increase

Comments by participants reflect the complexity of providing palliative care in this setting. The importance of education but also preparation of the family:

"I think more and more end of life care will be conducted in residential aged care facilities. I think we'll be doing that with support from our specialist palliative care teams. As far as the challenges go, maintaining training and knowledge on palliative care for people who work in the aged care sector. Some of the challenges are around the equipment. I think training needs to be ongoing and our organisation has started to provide ongoing training for them."

"Some families when they come to residential haven't even thought about it or discussed the absolute end of life aspect of things so I think that will be a constant challenge because we are finding increasingly the length of stay of people in residential aged care is getting shorter. Staff are having to increasingly have these conversations a lot earlier than they would have and it's not a one off conversation, it's an ongoing discussion. What we've found in a few recently, even towards the end, the family still really hasn't come to grips with it even though we've had our staff tell them 'listen, your family member is dying'. And we've have palliative care people come over and talk to them as well and we've got social work involvement in helping them cope with bereavement and everything; but it's like the penny hasn't dropped."

# Perceptions of way in which IT will change end of life care in the future and how the RAC [HUB] can integrate with or support these changes

The way in which increased use of IT will change end of life care and how these changes might support the use of the RAC [HUB] included:

- The increased uptake of electronic records that will also facilitate transfer of information between settings for advance care planning
- Increased access by individual staff to online education
- iPad/iPhone access at resident's bedsides

"I think the information technology, if we get electronic records up and happening, that will be a huge step forward."

"Well it means if somebody has an advance care plan and they've been in hospital and they come to the nursing home, that electronic record will come with them and will go in the ambulance with them wherever they go."

"If I've got an iPad in front of me or if I'm a resident and I have an iPad in front of me and I wanted to check on palliative care I could go straight on and look at the RAC Hub and look at all the information I need, couldn't I?"

"I think if we could get IT to be...to match up the sort of software that's needed to run these online learning modules that would be a good resource to get people really up to date with their skills and what not. I think it's got a real role there because you could just say, there's an online learning module you can go to."

"Easy to access best practice guidelines at their fingertips, the nurses with an iPhone sitting at the bedside can access it right there. That sort of thing."

"So when it is on the RAC website is it compatible for normal mobile technology? Are they compatible for the mobile pieces? I think the second challenge for us is getting our IT infrastructure up to support the changing technologies that we're facing and we're not there yet."

The increased use of IT would also help support families:

"I think it's okay having that there and saying to families, particularly – a lot of the families now who are IT savvy we're emailing them or we might say to them you might just want to – here are some websites that might help you understand what's happening to your loved one or something like that. I think that's a good idea, I think it's doable."

One participant did provide a word of caution about whether the use of handheld devices may lead to reduced RN numbers:

"My fear is that it could make things even more difficult. A lot of people are going to handheld palm pilots and hand held computers at the bedside; someone said to me that it would make things easier as they don't have access to many RNs so the care worker can access the RN at the bedside and explain what's going on, and the RN can assess whether she does need to come ...it could even make things better or worse, I don't know. If the facility brings in all these electronic forms of communication, then we may be able to reduce the number of staff but that would be a fear, something I would be concerned about. If they use it to access information and transmit information about the residents in a more timely manner, then it could be good. So there is good and bad about it."

#### Perceptions of whether the RAC [HUB] is a useful direction for CareSearch

Participants agreed that the RAC [HUB] is useful but only if people are aware of it. So it really is important to increase exposure and awareness.

"Good to have HUBS – everyone has a different skill set. I don't need to know what the GP knows."

"The profile does need to be lifted...I know about it simply because I'm...in education and I look for resources about clinical topics."

"If you're putting a lot of time and effort into setting up this Hub and not many people are using it then I think it's a waste of resources. I think having the Hub is important; but more importantly, having the public aware that it is there so that they can use it...I think it's important that the general public needs to know that this resource is available and... more importantly the people who are caring for them need to know how they can use it to provide the best care possible for people who are dying."

"I think we need to promote the RAC Hub more so that it's seen like Googling, anything – if I want to find something I just Google and I get that information readily, but to look at it like that; if they need something to know about palliative care I know exactly where I need to go and I can access it so easily. That's really how we should start to think about it."

#### **Suggestions for improving RAC [HUB]**

Suggestions for improving the RAC [HUB] included:

- Improve website navigation to the [HUB] e.g. button on the front page
- Include short video to orientate website visitors
- Include a website index
- Link with other educational resources
- Ensure videos no longer than 10 mins
- Include fact sheets one or two page summaries of evidence
- Look at terminology may not be appropriate to some religions
- Clearer information regarding important clinical issues such as the use of morphine or CPR
- Include information about younger people (e.g. with Huntington's disease) in residential aged care facilities (RACFs)
- Include a drug calculator
- Include facility to download videos and DVDs from RAC [HUB] onto RACF's learning management system
- Include facility to have competency assessments that RACFs can add own logo to

One comment related to the difficulty of locating the RAC [HUB] from the CareSearch home page.

"I find it difficult to get to the Residential Hub, because when you first open CareSearch, there's not a thing that says 'Residential Hub'. Just give me a button on the front page and it's not clearly indicated that you've got Hubs. You've got information for professional

people, information for clinical issues ... but I thought, where are the Hubs, there should be a button that says 'hubs'."

One participant suggested a "how to" video:

"They actually had a little video that orientated people to using CareSearch so they could log on, someone would talk them through some of the main areas. Maybe that's something they need to consider with the RAC Hub, to talk people through the different areas."

One participant thought the ability to download education resources from the RAC [HUB] would enhance their learning and the link to competency assessments was also suggested:

"The RAC Hub to be able to...like we have a learning management system, if I could upload the stuff from the RAC Hub, so videos and DVDs, onto my learning management system."

"It's about competency assessments. So...if I'm learning something, then wherever possible, we are required to produce evidence of that learning. So, yes, I've got the paper that says I've done one hour of theoretical component, but actually here is the skills competency for it."

Some specific clinical tools such as how to calculate drugs was a suggestion by one participant:

"Maybe a drug calculator, so I'm giving so much of this to their body weight, what do I actually need to be giving say for effective pain management."

Fact sheets that synthesise the information in a one or two page summary would assist staff who are time poor and also may not have the skills to synthesise the evidence into the clinical bottom line:

"One page, five minutes, that's it out and back to practice."

Strategies that CareSearch should be aware of to encourage the uptake of online evidence in the aged care workplace

Suggestions included:

- Making the information portable to mobile devices
- Holding discussion forums where staff could chat live to an expert
- Making information available in different languages for staff with literacy issues

# **Summary**

# **On-line survey**

Respondents predominately worked in residential aged care (70%) and were aged 50 years and over (60%). Both urban and rural areas of Australia were represented with over half of the respondents (57%) working in major cities. Respondents were also most likely to work in Victoria, New South Wales or Queensland.

Persons in management or registered nurses were most likely to participate in this survey.

Approximately 80% of people working in residential aged care indicated they utilised specialist palliative care services.

Of the 115 persons participating in the survey approximately 70% were aware of the RAC [HUB] – predominately through promotional materials and newsletters or publications. Of those aware of the site, over 80% had visited the RAC [HUB]. Those not visiting the site indicated that dedicated time and prompts to visit the site may facilitate usage.

Over 50% of respondents who visited the site did so at least once a month and 63% of this group reported the site was "somewhat easy" to navigate.

The most commonly visited sections of the RAC [HUB] are "care issues" and "literature and resources" with over 90% of visitors accessing these sections. Between 49 and 57% of the sample found these sections "very useful". The least commonly visited section by RAC and non-RAC groups were "for residents and families" and "what's new in RAC", respectively. The "facility/quality" and "communication" sections were least likely to be nominated as "very useful" by the RAC and non-RAC groups, respectively.

Of the 65 respondents visiting the RAC [HUB], almost 90% were aware of the Hub newsletter and 80% were registered to receive the email.

Approximately 74% of those visiting the RAC [HUB] reported they had used information they found on the site. This information was predominately used for personal development. Respondents were also most likely to find the information "very useful" for personal development and discussions with other health professionals. Of the 35 respondents who had both used information from the Hub and worked in some form of palliative care service, 66% stated they had used the information to make changes in palliative care practice. These changes related to education/discussion with staff and families; developing organisational structures, policies and procedures; and improving clinical practice.

Just under 10% of RAC [HUB] users indicated they would change something about the RAC [HUB]. These changes related predominately to navigational issues. Suggestions to improve the site were made by 15% of users – most suggestions related to increasing information on

certain topics. Several suggestions were made to raise the RAC [HUB] profile amongst stakeholders and these included mail outs to facilities and promotion through social media, key stakeholder organisations, and local events.

## **Telephone interviews**

Survey participants represented a wide cross section of those working in clinical, leadership and policy positions. All agreed on the usefulness of the RAC [HUB] to promote and improve palliative care in the residential aged care setting.

Awareness and promotion of the RAC [HUB] was seen as critical and feedback indicated that current promotional activities may not be maximising the exposure of clinical staff to the RAC [HUB]. A suggestion for improving this exposure included linking more with peak body organisations to provide cross fertilisation. The promotion of a link on organisations intranet directly to Caresearch and more specifically the RAC [HUB] was seen as a strategy for promotion. It appears from the survey results that once users were aware of the RAC [HUB] then they were likely to use the information in practice. One issue was the visibility of the RAC [HUB]'s or other hubs on the Careserach home page. Time poor clinicians are looking for an obvious button or link to take them directly to the relevant area. Within the Hub homepage there should be a quick "how to navigate the Hub" video, showcasing the relevant areas so users can go directly to the desired area.

Significant barriers to using online resources including the RAC [HUB] are those difficult to resolve by Caresearch. That is time poor staff with limited access to computers, lack of IT infrastructure or lack of confidence in searching and finding online evidence. Linkages with the peak body organisations to promote the uptake of evidence and how to use online resources may assist in alleviating some of these issues. Interestingly, one of the ways suggested to overcome some of these barriers was the move by staff working in RACFs to using mobile technology. The continued move by organisations to electronic records will upskill staff in RACFs as well as potentially provide organisations with linkages to evidence based resources.

Synthesis of information into one or two page fact sheets on clinical topics was seen as a option to increase the use of evidence within practice. These could be similar to those produced by the Joanna Briggs Institute. Ideally these could be linked to alerts within electronic record systems.

The broader challenges faced within the sector of providing end of life care can be to some degree addressed by the RAC [HUB]. These include providing training resources for staff, providing support to families about end of life discussions and providing consistent information to other health professionals such as General Practitioners so everyone is on the same page. Short 10 minute videos on common end of life issues would be a good introduction to the evidence base and may encourage users to look further within the RAC Hub for supporting information.

### **Recommendations**

The main recommendations from this evaluation include:

- Look at options to assist navigation i.e. button on Caresearch homepage
- Educate users on how they can fully utilise the resources provided on RAC [HUB] this may be in the form of an introductory video
- Promote lesser used sections of the RAC [HUB] in the newsletters or promotional materials
- Seek to further develop sections identified as less useful and include new topics that are relevant to the sector i.e. Care of younger residents
- Provide fact sheets or synthesised information on clinical topics with links to the evidence base
- Investigate further promotional opportunities for the RAC [HUB] and CareSearch across both the aged and palliative care sector
- Investigate the use of the RAC [HUB] on mobile technology
- Investigate the linkage of evidence to online records

# **Appendix 1: On-line survey**

Very easy

On-lir	On-line survey						
1. Are you aware that CareSearch has a RAC [HUB]?							
0	Yes						
0	No						
(If q1=	(If q1=No, skip to q25)						
2. Ho	w did you find out about the RAC [HUB]?						
0	Recommended by a colleague						
0	Promotional materials						
0	Newsletters or publications						
0	Conference or presentation						
0	Internet search						
0	Other – please provide further information						
3. Hav	ve you visited the RAC [HUB]?						
0	Yes						
0	No						
(If q3=	=Yes, skip to q6)						
	o, why haven't you used it? <i>(Tick as many as applicable)</i> I don't know what's on it						
0	I don't think it would be relevant to me						
0	I'm not good at using the computer and searching the internet						
0	I'm not interested in web-based resources						
0	I don't have time						
0	I have only just heard about it						
0	Its not useful to me						
0	Other – please provide further information						
5. Wh	at would encourage you to use it?						
(Go to	o q25)						
6. Apı	proximately how often do you visit the RAC [HUB]?						
0	I have only visited once						
0	Once or twice a year						
0	Every three or four months						
0	Once a month						
0	More than once a month						
7. Is t	he format of the RAC [HUB] easy to navigate?:						

Somewhat easy

Not easy

Not sure

0

0

0

8. Which sections of the RAC [HUB] have you visited, and how useful was each of the sections?					ne
Sections:	Very useful	Useful	Not	useful	Haven't visited
People working in RAC	0	0		0	0
Care issues	0	0		0	0
Recognising resident's needs	0	0		0	0
Facility/ quality issues	0	0		0	0
Communication	0	0		0	0
For residents and families	0	0		0	0
Literature and resources	0	0		0	0
What's new in RAC	0	0		0	0
9. Are you aware of the RAC [HUB] news	letter?				
O Yes					
O No					
10. Are you registered to receive the RAC	C [HUB] nev	vsletter?			
O Yes					
O No					
11. If you have visited the RAC [HUB], ha	ve you use	d any of the	e informati	on you fou	ınd?
O Yes					
O No					
(If q11=No, skip to q16)					
12. If you used the information, what was	s it for and v	vas it usefu	ıl?		
	Very Useful	Somewhat Useful	Not Useful at all	Not Applicable	
Teaching others	0	0	0	0	
Provide handouts	0	0	0	0	
Include in newsletters	0	0	0	0	
To change an area of practice	0	0	0	0	
To disseminate to others	0	0	0	0	
As a discussion point	0	0	0	0	
To support an idea or argument	0	0	0	0	
To discuss with a manager	0	0	0	0	
For your own development	0	0	0	0	
To discuss with another health professional	0	0	0	0	
Other	0	0	0	0	
13. If you listed 'other' above, please des	cribe				
<del>_</del>					
14. Has the information in the RAC [HUB] care practice within your service?  O Yes	] assisted y	ou to make	any chan	ges in palli	ative

0	No
0	Not applicable
15.	If yes, please give an example
	Is there anything that you would change about the information and resources on the
C	C [HUB]? Yes
0	No
17.	If yes, what changes would you make?
18.	s there anything that you would like to see on the RAC [HUB]?
0	Yes
0	No
19.	If yes, what would you like to see?
20	Do you, or would you, recommend the RAC [HUB] to your colleagues?
0	Yes
0	No
21. the	Do you have any ideas on how to promote the RAC [HUB], or increase subscriptions to RAC [HUB] Newsletter?
22.	Do you have any suggestions for improving the RAC [HUB]?
23.	Is there anything else that you would like to add a comment on?

We would now like to find out a little bit about you.			
24.	Where do you usually access the RAC [HUB]?		
0	At work		
0	At home		
0	At work and at home		
0	At the Library		
0	From my phone		
25.	Age?		
0	18 – 29		
0	30 – 39		
0	40 – 49		
0	50 – 59		
0	60 +		
26. job	If you work in Australia, what is the Postcode of your primary ?		
27.	If you work in country other than Australia, please record it.		
28.	Are you currently working in Residential Aged Care?		
0	Yes		
0	No		
(If q	28=No, do not answer q30 and q31)		
29.	What is your main role in your primary workplace?		
0	Clinical Nurse Specialist		
0	Nurse Practitioner		
0	Registered Nurse		
0	Endorsed Enrolled Nurse or Enrolled Nurse		
0	Personal Care Attendant / Nurse Assistant		
0	Care Director / Director of Nursing		
0	Nurse Unit Manager		
0	Clinical Educator		
0	Student Nurse		
0	Allied Health		
0	Pastoral Care		
0	Diversional Therapist		
0	Researcher/ Academic		
0	Project Officer		
0	Other – please describe		
30.	Do you access support from a specialist palliative care service?		
0	Yes		
$\sim$	NI.		

31. W	31. What do you currently do to support palliative care in your Residential Aged Care				
Facility? (Tick as many as applicable)					
0	Education				
0	Policy documents/ guidelines				
0	Advance care planning				
0	Family meetings/ case conferences				
0	Use of an end of life care pathway				
0	Other – please describe				

# **Appendix 2: Telephone interview**

- 1. Can you tell me a bit about your current role and how it relates to Residential Aged Care?
- 2. My next questions relate to the RAC [HUB] in the CareSearch website. Are you aware of this resource? Have you used the RAC [HUB] and what do you think about it?
- 3. How do you think the RAC [HUB] can provide evidence about end of life care that would assist people working in residential aged care?
  Prompt: do staff understand evidence-based literature; can they critique evidence?; is the information useable?
- 4. What do you believe are the most significant barriers for people working in residential aged care with respect to using on-line resources?
  Prompts: access to computers/internet; computer literacy; time; who would take on this role?; lack of support from employers to provide time; What are the priorities in RACFs and does keeping up with evidence-based practice come into it?
- 5. What do you believe are the best ways of addressing these barriers?
- What challenges does providing end of life care pose for providers of residential aged care in the future?
   Prompts: staff knowledge; funding; staffing time; self-efficacy?; ageing population/ baby boomers
- 7. How do you think information technology will change end of life care in the future and how can the RAC [HUB] integrate with or support these changes?

  Prompts: IPads/IPhones (at point of care); electronic documentation; consumers have increased access to information; timeliness of information; up-to-date information
- 8. Do you think the RAC [HUB] is a useful direction for CareSearch to go into? Yes/No and why? Prompt: dedicated area for RAC
- 9. How could the RAC [HUB] be improved?
- 10. Are there are any strategies that CareSearch should be aware of to encourage the uptake of online evidence in the aged care workplace?
  Prompt: best practice information sheets
- 11. Is there anything else that you would like to add or comment on?

# Appendix 3: On-line survey participant information sheet and consent

#### **Principal Investigator:**

Associate Professor Deborah Parker

University of Queensland/ Blue Care Research and Practice Development Centre

#### **Project Manager:**

Karen Clifton

University of Queensland/ Blue Care Research and Practice Development Centre

As a registered user of the RAC [HUB] (or interested party), you have been invited by CareSearch to participate in an on-line evaluation of the RAC [HUB]. The University of Queensland/ Blue Care Research & Practice Development Centre (RPDC) has been engaged by CareSearch to conduct this evaluation.

#### Your involvement in the project

Your participation in this project will involve completing a brief 10 minute electronic, web-based survey. You will be asked about the impact and effectiveness of the RAC [HUB] web pages. Some brief demographic information will also be collected.

#### Your voluntary participation

Participation in this project is completely voluntary. If you prefer not to answer particular questions in the survey that is fine – an incomplete interview will still be useful to our research. You can choose to withdraw from the project at anytime without comment or penalty and your decision will be respected. If you choose to withdraw, any information we have already collected will not be used. Your decision to participate will in no way impact upon any current or future relationship with the University of Queensland or with CareSearch.

#### Benefits from the project

Although participation in this project may not benefit you directly, in the long term it may assist in improving information resources for those delivering, or experiencing, palliative care in residential aged care settings.

#### **Risks**

There are no risks associated with your participation in this project.

#### Confidentiality

Your identity, your contact details and the information you provide will remain private and confidential. No publication from the study will include any information that could identify you.

#### Storage of data/information

Data held on the CareSearch Research Data Management System (RDMS) is protected by confidentiality agreements with the Information Technology and webhost company. Data will be directly exported by the UQ researcher to their computer for analysis using https transmission. Once

downloading is completed, the data will be deleted from the CareSearch RDMS. The electronic data will be password protected, accessible only to the research staff on the study. Seven years after completion of the study all materials will be disposed of as confidential waste.

#### Feedback available to you

A summary of findings will be included in the RAC [HUB], @CareSearch and Nurses [HUB] newsletter.

This study adheres to the Guidelines of the ethical review process of The University of Queensland. Whilst you are free to discuss your participation in this study with me (contactable on (07) 3377 3310 or email: <a href="mailto:deborah.parker@uq.edu.au">deborah.parker@uq.edu.au</a>) or our project manager Karen Clifton contactable on (07) 3720 5405 or email <a href="mailto:k.clifton@uq.edu.au">k.clifton@uq.edu.au</a>, if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on (07) 3365 3924 or email: <a href="mailto:humanethics@research.uq.edu.au">humanethics@research.uq.edu.au</a>

I declare that I have given my *Informed Consent*, as evidenced by the following:

- 1. I have been provided with and have read and understood the Participant Information Sheet.
- 2. The purpose and the benefits of the project have been explained to me.
- 3. Details of my involvement in the project and any risks have been explained to my satisfaction.
- 4. I have had an opportunity to discuss my taking part in this project with the researcher.
- 5. I understand that completing the survey may take 10 minutes.
- 6. I am aware that I should retain a copy of the *Participant Information Sheet* for future reference.
- 7. I understand that
  - I am free to withdraw from the project at anytime and my decision will be respected.
  - All data will be securely stored during and after the project.
  - Information gained in this project will be reported, but I will not be identified.
- 8. Any information I give to the researcher will be treated in the strictest confidence.
- 9. I know who to contact to answer any further questions I may have concerning my participation in this project.
  - ☐ I have read the *Informed Consent* information and I hereby consent to participate in the research project titled: **CareSearch RAC [HUB] Evaluation**

# Appendix 4: Telephone interview participant information sheet and consent

#### **Principal Investigator:**

Associate Professor Deborah Parker

University of Queensland/ Blue Care Research and Practice Development Centre

#### **Project Manager:**

Karen Clifton

University of Queensland/ Blue Care Research and Practice Development Centre

Dear

The University of Queensland/ Blue Care Research & Practice Development Centre (RPDC) has been engaged by CareSearch to provide quality improvement information related to the CareSearch RAC [HUB]. The RPDC proposes to interview a range of professional providers and aged care leaders to identify the role and impact of the RAC [HUB] for the sector.

#### Your involvement in the project

If you are willing to share your experiences, we can do this with a telephone interview of approximately 15-30 minutes. You will be asked to discuss how the RAC [HUB] could best support the sectors' information needs.

#### Your voluntary participation

Participation in this project is completely voluntary. If you prefer not to answer particular questions in the interview that is fine – an incomplete interview will still be useful to our research. You can choose to withdraw from the project at anytime without comment or penalty and your decision will be respected. If you choose to withdraw, any information we have already collected will not be used. Your decision to participate will in no way impact upon any current or future relationship with the University of Queensland or with CareSearch.

#### Benefits from the project

Although participation in this project may not benefit you directly, in the long term it may assist in improving information resources for those delivering, or experiencing, palliative care in residential aged care settings.

#### Risks

There are no risks associated with your participation in this project.

#### Confidentiality

Your identity, your contact details and the information you provide will remain private and confidential. No publication from the study will include any information that could identify you.

#### Storage of data/information

The information collected during the study, including the audio-recording of this interview, will be kept in a locked filing cabinet and all electronic data will be password protected, accessible only to the research staff on the study. Seven years after completion of the study all materials will be disposed of as confidential waste.

#### Feedback available to you

A summary of findings will be included in the RAC [HUB], @CareSearch and Nurses [HUB] newsletters.

This study adheres to the Guidelines of the ethical review process of The University of Queensland. Whilst you are free to discuss your participation in this study with me (contactable on (07) 3377 3310 or email: <a href="mailto:deborah.parker@uq.edu.au">deborah.parker@uq.edu.au</a>) or our project manager Karen Clifton contactable on (07) 3720 5405 or email <a href="mailto:k.clifton@uq.edu.au">k.clifton@uq.edu.au</a>, if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on (07) 3365 3924 or email: <a href="mailto:humanethics@research.uq.edu.au">humanethics@research.uq.edu.au</a>

Thank you

I declare that I have given my *Informed Consent*, as evidenced by the following:

- 1. I have been provided with and have read and understood the *Participant Information Sheet*.
- 2. The purpose and the benefits of the project have been explained to me.
- 3. Details of my involvement in the project and any risks have been explained to my satisfaction.
- 4. I have had an opportunity to discuss my taking part in this project with the researcher.
- 5. I understand that completing the interview may take 30 minutes.
- 6. I understand this interview will be audiotaped for later transcribing.
- 7. I am aware that I should retain a copy of the *Participant Information Sheet* for future reference.
- 8. I understand that
  - I am free to withdraw from the project at anytime and my decision will be respected.
  - All data will be securely stored during and after the project.
  - Information gained in this project will be reported, but I will not be identified.
- 9. Any information I give to the researcher will be treated in the strictest confidence.
- 10. I know who to contact to answer any further questions I may have concerning my participation in this project.

I have read the *Informed Consent* information and I hereby consent to participate in the research project titled: **CareSearch RAC [HUB] Evaluation** 

Name		
Signature	Witness	
Date	Date	