

## **Title**

Preferences of patients with palliative care needs and their families for engagement with service improvement work within the hospital setting: A qualitative study

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## **Abstract**

### **Background**

There is growing recognition of the importance of involving patients and families with lived experiences of illness in healthcare service quality improvement, research, and implementation initiatives. Ensuring input from people with palliative care needs is important, but how to enable this is not well understood.

### **Aim**

To seek the perspectives of Australian patients with palliative care needs, and their family members, to elicit their views on how to best contribute to inpatient palliative care quality improvement initiatives.

### **Design**

An exploratory qualitative study, using semi-structured interviews.

### **Setting/participants**

Eligible participants were adult patients with palliative care needs receiving care within a hospital setting, and their family members. Recruitment occurred through: five hospitals in New South Wales, Australia; and snowballing.

### **Results**

Fifty participants took part (21 patients and 29 family members). Results confirmed four themes: 1) Mechanisms for providing feedback about care quality need to be supportive and individualised; 2) The clinician-patient/family power imbalance makes real time feedback challenging to provide; 3) Willingness to contribute varies according to diagnosis, timing and role; and 4) Face to face feedback is preferred for health service improvement work.

### **Conclusions**

Enabling meaningful consumer input to quality improvement requires careful consideration due to the unique requirements of the palliative care population. Embedding tailored outcome and experience measures to inform real-time care provision coupled with focused opportunities for input into service improvement may best foster improvements in inpatient palliative care, founded in what matters most for people requiring this care.

## **Key words**

Palliative care, hospital, terminal care, consumer participation, qualitative research, patient-centred care, quality improvement, quality of care

## **Key statements required by Palliative Medicine**

### **What is already known about the topic?**

- Consumer engagement to guide health service reform is required with the need for better methods to enable meaningful consumer engagement well described;
- Developing a framework for involving palliative care consumers in informing ongoing improvement work across the sector is needed to ensure the reform process remains aligned with patient and family priorities.

### **What this paper adds?**

- Four key themes for consideration when designing a consumer engagement strategy within palliative care: Mechanisms for providing feedback about care quality need to be supportive and individualised; The clinician-patient/family power imbalance makes real time feedback challenging to provide; Willingness to contribute varies according to diagnosis, timing and role; Face to face feedback is preferred for health service improvement work.
- An outline of the need to consider two key aspects for consumer engagement: feedback to inform current care planning and provision; and feedback to enable service level improvements.
- Evidence of a strong preference for an identified key person with whom patients with palliative care needs and their families can liaise with on a day-to-day basis in relation to care provision.

### **Implications for practice, theory or policy?**

Recommendations for future practice centre around three key areas:

1. Embed mechanisms for real-time feedback that impacts immediate care provision through targeted outcome and experience measurement relevant to those with advanced serious illness.
2. Establish mechanisms for feedback post-discharge with explicit consideration of timing for people with advanced serious illness. Feedback needs to align with a time

of illness stability or after a respectful period post-bereavement and ought to provide an opportunity for both an interview and/or survey format.

3. Enable meaningful and targeted representative roles for patients with advanced non-malignant serious illnesses and bereaved family members for longer term input and co-design work for health service improvement.

## Introduction

There is a growing imperative to involve consumers (patients and families) and consumer representatives (people with lived experiences) in service redesign, research and implementation initiatives.<sup>1-5</sup> Varied calls for consumer participation are made referring to input from individual contributions through to representation at organisational, jurisdictional and national levels.<sup>5,6</sup> Understanding how to enable meaningful consumer input both broadly and in relation to palliative care specifically, to impact positively on service development, provision and outcomes, remains elusive.<sup>2-4, 7-9</sup>

The term consumer can be used collectively to refer to patients, carers and organisations representing the views of consumers.<sup>10</sup> Levels of consumer engagement vary in terms of depth of control and actions used.<sup>11</sup> While terminology used to describe these levels of engagement vary globally, there are similarities at the conceptual level in that consumers can provide information or consultative advice, through to working in more of a partnership model, through to a consumer-led process.<sup>11</sup>

Internationally, consumer engagement has been noted as central to enabling system improvements, ensuring an ongoing focus on person-centred care and improving health outcomes.<sup>12</sup> Over the past two decades many high-income countries have made significant progress on engaging consumers to guide health service reforms.<sup>1, 4, 6, 7</sup> However, the need for better methods to enable meaningful engagement continues to be identified as a key priority globally.<sup>2, 6, 12</sup> Within Australia, co-design work with consumer representatives is in its infancy<sup>4</sup> and understanding how to best support partnership working more broadly requiring attention.<sup>5</sup> A need to see embedded consumer engagement emerging from policy and intent to practice is noted.<sup>4</sup> Consumers Health Forum of Australia calls for consumers to be: involved in all levels of decision making; enabled to make informed decision and choices; trusted and respected; engaged in partnership working for health service planning and improvement; and to *'serve as the engine room for improving and innovating health and social care services'*.<sup>14,p5</sup> However, methods to achieve authentic engagement require greater understanding<sup>6, 7, 9</sup> to disrupt the current status where clinicians, industry providers and bureaucrats continue to dominate decision-making and related outcomes.<sup>4, 5</sup> Eight key roles are noted within consumer representative responsibilities including: change agent; policy influencer; community mobiliser; co-designer; research collaborator; educator; expert patient; payer and contributor.<sup>4</sup> How to enable such roles within palliative care service provision and improvement activities, given patients are so unwell and family members are often stressed, is unclear. Although palliative care is philosophically person-centred, routine engagement with consumers to inform change and development in service provision is not well described.<sup>1</sup> Recommendations for explicit guidance are made inclusive of a call for

future research to focus on how to foster better alliances between consumers and palliative care practitioners, academics and policy makers.<sup>1</sup>

### **Aim**

To seek the perspectives of Australian patients with palliative care needs, and their family members, to elicit their views on how to best contribute to inpatient palliative care quality improvement initiatives.

### **Method**

#### ***Design***

An exploratory qualitative study, using semi-structured interviews. Detailed methods have been described elsewhere in relation to another analysis conducted on the same dataset.<sup>13</sup> The interview questions were open-ended in an attempt to enable a depth of understanding and allow points of interest to be followed as they arose. This allowed for a systematic collection of data to inform understanding and study outcomes.

#### ***Participants***

Given the vulnerability of this population (hospitalised adult patients with palliative care needs and their family members), a co-design process was undertaken over 18-months with consumers (n=11) to determine the study's eligibility criteria, sampling and recruitment processes. This process included five panel meetings with a focus on co-designing optimal strategies for identifying, approaching and recruiting people with palliative care needs and their families to participate in this research. Detailed field notes were documented at each meeting to inform protocol development. Details of this co-design work are detailed elsewhere.<sup>14</sup> The eligibility criteria for this study reflects this advice (Textbox 1).

#### **Textbox 1 – Inclusion and exclusion criteria for participant eligibility**

<b>Inclusion criteria</b>	<ol style="list-style-type: none"> <li>1. Adult with palliative care needs, as defined by: <ul style="list-style-type: none"> <li>▪ clinical indicators of one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT™);<sup>15</sup></li> <li>▪ Australia-modified Karnofsky Performance Status (AKPS)<sup>16</sup> score between 30 and 70;</li> <li>▪ 1 or more admissions to hospital within the previous 12 months.</li> </ul> </li> <li>2. Awareness that they have a serious chronic illness.</li> <li>3. Comfortable talking about their serious chronic illness and related care needs.</li> <li>4. Willing to give verbal informed consent to participate in the study.</li> </ol>
<b>Exclusion criteria</b>	<p>Unable to give informed consent or complete an interview due to:</p> <ul style="list-style-type: none"> <li>• limited English proficiency;</li> </ul>

	<ul style="list-style-type: none"><li>• cognitive impairment.</li></ul>
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## **Setting**

Recruitment occurred through five hospitals (metropolitan (n=4) and remote (n=1)) in New South Wales, Australia, as well as via snowballing.

## **Research team**

The researchers included a palliative care nursing doctoral candidate (CV) supported by experienced researchers with oncology, palliative care and qualitative research expertise (JLP and TL). The first author's reflections were documented in a reflexive journal after each interview to inform discussions with the research team when uncertainties arose, to support rigour.<sup>17, 18</sup>

## **Recruitment**

Senior clinicians known to each patient were asked to identify eligible participants (purposive sampling) at each recruitment site. This approach was chosen to ensure participants were competent to answer the key research questions based on real-world experiences of care. If eligible, clinicians provided study information to the potential participant and gained verbal consent to provide their details to the research team. Once received, the researcher (CV) contacted the potential participant to discuss study details. Recruitment for bereaved family members occurred via established bereavement care provider and palliative care research networks that include consumer representatives.

## **Data collection**

Phone interviews (October 2018 – October 2019) were chosen to limit burden for unwell participants and busy caregivers. The interview guide was planned to make participants feel at ease and promote depth of conversation, given phone interviews can sometimes generate less data depth compared with face to face interviews.<sup>19, 20</sup> An interview guide focused on understanding areas of importance for safe, high quality care within the hospital environment (reported elsewhere)<sup>13</sup> as well as understanding how participants may like to engage in service improvement. This paper reports the questions and data related to improvement work only (Textbox 2).

## **Textbox 2 - Semi-structured interview question route**

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Interviewer preamble: We are also trying to think about how we might help patients and families give regular feedback to us about the care that is provided whilst they are in hospital, so we could better meet your needs.

1. What would have been the best way to ask for this information about your/your family member's care whilst you were in hospital – Eg. through an interviewer, through a paper survey, through an electronic device like an iPad or tablet or touch screen or mobile phone or would you just prefer staff to speak to you / your family member or carer?
  2. Would you prefer to provide this information whilst you/your family member is in hospital in real-time, or after you/your family member is discharged?
  3. We know that involving patients and families in designing clinical care is very important. You have had a number of encounters with hospital services and I wondered what your thoughts are about providing feedback or working with us to improve our services?
  4. Would you prefer to provide feedback face to face, or via the phone or through some form of video-conferencing? What could we do to make your participation as easy as possible?
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Interviews were audio-recorded, transcribed verbatim and field notes taken. When no new information emerged, data saturation was considered reached.

Demographic data were collected to describe the study sample, including: age; gender; highest level of education; nationality; metropolitan or rural location and diagnosis.

### ***Data analysis***

Content analysis was used to systematically organise available data into a format able to inform whether and how people with palliative care needs would like to contribute to health service improvement work.<sup>18</sup> This format was informed by the question guide (textbox 2). Once the data were ordered they were further analysed for recurrent concepts and themes to inform study outcomes.<sup>21, 22</sup> Transcripts were checked against audio-files at the completion of each interview, before being entered into NVivo 12 (QSR International) for management. Analysis used the following steps:

1. Data immersion:<sup>21</sup> Each interview was listened to and read twice before line-by-line analysis. Field notes were integrated onto the transcripts, to inform analysis.
2. Coding:<sup>21</sup> an inductive approach was used. Coding was completed by one reviewer (CV) with review by members of the research team (JP and TL) to resolve any areas requiring consensus.



3. Thematic analysis: Thematic analysis of all data (transcripts and field notes) occurred<sup>23</sup> in accordance with the four-step process articulated by Green and Willis inclusive of data immersion, coding, categorising and generation of themes

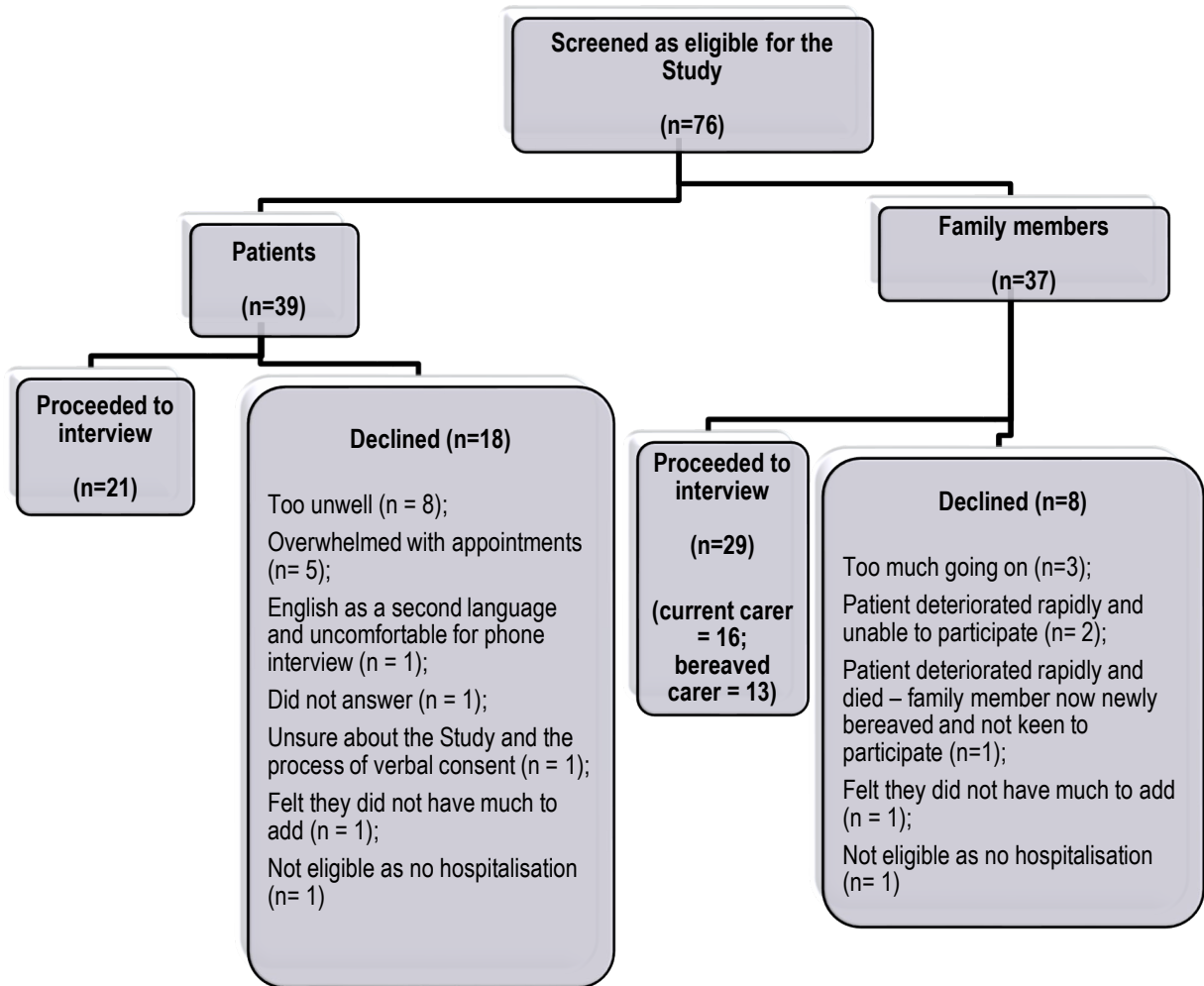
### ***Ethics***

Ethical approval was granted by St Vincent's Hospital Sydney, Human Research Ethics Committee Ref. No. 2019/ETH03307. Participants provided informed verbal consent to participate. The Standards for Reporting Qualitative Research (SRQR)<sup>24</sup> informed reporting of results with 21/21 standards addressed.

### **Results**

Seventy-six participants were eligible for interview, of whom 50 (66%) completed interviews (Refer Figure 1). Patients tended to be female (n=12, 57%), White Australian (n= 13, 62%) and metropolitan based (n= 18, 86%) (Refer Table 1). Families also tended to be female (n= 11, 69%), White Australian (n= 19, 56%) and metropolitan based (n= 11, 69%). Bereaved family members were also predominantly female (n= 10, 77%), White Australian (n= 9, 69%) and metropolitan based (n= 11, 85%) but predominantly reflected experiences of those dying from a malignant diagnosis (n= 13, 85%). 79% (n= 23) of family members (current or bereaved) had a Bachelor's degree or higher.

Interview lengths ranged from 17 minutes (patient interview) through to 126 minutes (bereaved family member interview) with the median interview length for patients being 45 minutes, family members 47 minutes and bereaved family members 70 minutes.



**Figure 1: Overview of participation for those screened as eligible for this study**

**Table 1 – Sample characteristics (n=50)**

	<i>Age (Yrs)</i>	<i>Gender</i>	<i>Highest level of education</i>	<i>Nationality</i>	<i>Metropolitan or rural</i>	<i>Diagnosis</i>
<i>Patient sample (n=21)</i>	Median: 69	Male: n=9	Post school education: n=8	Australian: n=14 of whom one identified as an Aboriginal Australian	Metropolitan: n=18	Malignant n=10
	Range: 45-82	Female: n=12	Yr 12 schooling: n=9 Yr 9 schooling: n=4	New Zealander: n=1 Sri Lankan: n=1 Filipino: n=1 South African: n=1 Austrian: n=1 Maltese: n=1 Italian: n=1	Rural: n=3	Non-malignant n=11
<i>Family sample (n=16)</i>	Median: 54.5	Male: n=5	Post school education: n=11	Australian: n=9 Indigenous Australian: n=1 Filipino: n=2	Metropolitan: n=11	Malignant n=8
	Range: 30 - 78	Female: n=11	Yr 12 schooling: n=2 Yr 9 schooling: n=3	English: n=1 Chinese: n=1 Scottish: n=1 Sri-Lankan: n=1	Rural: n=5	Non-malignant n=5 Both n=3
<i>Bereaved family sample (n=13)</i>	Median: 56	Male: n=3	Post school education: n=12	Australian: n=9 Indigenous Australian: n=1 English: n=3	Metropolitan: n=11	Malignant n=9
	Range: 33 - 69	Female: n=10	Yr 12 schooling: n=1		Rural: n=2	Non-malignant n= 2 Both n=2

Illustrative participant quotes are reported alongside all analysis to enhance transparency and trustworthiness of data presentation.<sup>18</sup> A broader representation of illustrative quotes is available in Appendix 1.

Four themes emerged from the data analysis: Providing feedback about care quality needs to be supportive and individualised; The clinician-patient/family power imbalance makes real

time feedback challenging to provide; Willingness to contribute varies according to diagnosis, timing and role; Face to face feedback is preferred. Details about each theme are summarised below:

### **Mechanisms for providing feedback about care quality need to be supportive and individualised**

Participants described the importance of feeling supported and having a key person they could speak with in relation to care quality, their concerns and/or information needs.

*... I don't think I would have gone entering stuff into an I-pad sitting there...I think when you're going through the process of whatever you're in hospital for and everything's happening around you, I think personal communication is probably the best thing. (Bereaved family 4, 69yr female carer for friend with malignancy)*

Being preoccupied with other matters, or being too unwell to provide written feedback, were the main reasons participants preferred a personal approach, which enabled them to make a personal connection and to feel supported to discuss issues or concerns. Complexity of needs and experience made it difficult to capture in a written form, even using a tablet computer.

*I think a patient liaison person to come and have a conversation. ... Because I think about mom. Mom's cognition, when she's really crook, she can't even write. Her words are all jumbled up. She can't press a keyboard. (Family 5, 50yr female carer for mother with malignancy)*

In contrast, a few participants reported use of an electronic device to elicit feedback to be acceptable.

*... that's where the system is now. It's all electronic, and that would be really helpful to put things there and say, "Well, I've put it on the iPad or whatever," and they could check it. If they come in, they're checking the patients every hour. Well, they can be checking that as well. ..Especially if you can't be there all of the time. (Family 16, 59yr female carer for father with malignancy and non-malignant illness)*

Participants spoke about their experiences in seeking help when needed, within the ward environment. They described the importance of being provided with details about key ward leaders, the broader clinical team and how they could be contacted.

*I think it's about just having that one go-to person, be it a medical person, be it a nurse, be it a CNC (Clinical Nurse Consultant), be it a social worker, but just someone who you know you can go to, no matter what. (Bereaved family 3, 43yr female carer for brother with non-malignant illness)*

Participants desired proactive contact by a clinician who took responsibility to check in regularly to determine if all care needs were being met.

*If somebody, if there was a care coordinator or team leader or somebody that just actually came in and spoke to every patient at least once a day, to check that they were okay. If there was anything that they were unhappy with, just to think somebody was looking in at least once a day and checking that everything was okay, I think would've been good...But somebody who has some authority to actually do something if there was something wrong... So I think it really needs to be somebody that's got at least some ability to influence the ongoing care. (Bereaved family 4, 69yr female carer for friend with malignancy)*

Participants noted it would be helpful to have a mechanism that enabled them to communicate directly with the clinical team. They suggested a whiteboard at the patient's bed or locker, or a notepad and pen secured to the console. Family members noted this would enable them to be heard even when they are not physically present (for example, noting dietary preferences for a father with dementia) as well as being able to note specific queries and/or information needs they would like addressed.

*I'd like a noticeboard for the actual carer to write whatever they want to. (Bereaved family 12, 54yr male carer for father with malignancy)*

Patients specifically noted this would enable them to write down their thoughts / questions / concerns so this can be used at the time their medical team visits.

*One problem I did have is that I would always have questions to ask and I'd always forget when I was talking to the doctors or the nurses or whatever. I'd say pen and paper for me, just writing it all down. (Patient 1, 48yr male with malignancy)*

### **The clinician-patient/family power imbalance makes real time feedback challenging to provide**

Patients and family members reported finding it difficult to speak up in real-time when unhappy about care as they worried there might be negative repercussions.

*When you have a nurse who's just not the best of nurses, as far as you're concerned, you do think about complaining or saying something because, well, you don't know what the repercussions will be. That is a situation. It does come into play (Patient 18, 71yr male with non-malignant illness)*

Some participants noted this concern might be more significant for older patients, noting the power differential between clinicians and patients which can lead to patients feeling vulnerable and afraid.

*They just kind of shrink away to a shadow of themselves while they're there. They're frightened of the nurse. Often, especially with the elderly ones, they're frightened of the nurses. They think they're going to get in trouble from them if they question anything or if they do anything, or if you question anything, kind of thing. Which is very sad why they've got this fear of them (Bereaved family 2, 52yr female carer for husband with malignancy and father with non-malignant illness)*

Family members spoke about the challenge they felt in advocating for the patient without upsetting the clinical team. They worried that being seen as 'difficult' might make clinicians less responsive to needs.

*Where do I draw the line to be their daughter and support, versus coming in and overstepping clinicians and saying, "I don't think you're doing this right. I think you should be doing this. Or can you explain to me why this hasn't happened this way?" I just feel a little bit like I'm not sure at what point mom and dad are going to think I'm being overbearing, rude, pushy, those kind of things, because they may perceive that it might impact the care that they get. If the staff think, "Oh, their daughter's a pain in the bum, asking too many questions," yeah, I don't want them to be in the position where they feel awkward about the conversations that I have (Family 5, 50yr female carer for mother with malignancy)*

Participants preferred being contacted for service feedback after discharge, rather than in real-time. However, the timing of these calls was crucial, given the temporal nature of palliative care, with participants less welcoming this contact if the patient was unstable or deteriorating and requiring a lot of care.

*To be honest, we were just so focused and so busy getting her home, so I probably would have said to somebody at a time, "Can you not call me?" So it would've been probably more of a hindrance than a help. Like if she had come home and been okay and a bit more stable and normal, it would have been fine, but the fact that she come home and had issues, that I would've been like, "No, please don't call me." (Bereaved family 10, 43yr female carer for mother with malignancy)*

Similarly, post-discharge contact wasn't seen as useful if purely for quality improvement, but rather needed to be part of a more authentic clinical encounter focused on checking in and making sure the patient and family had the supports they required.

*If it was a quality control thing, like, "Hey, give us some feedback," no. That wouldn't be appreciated. But if it was a, "Hey, we just want to see how you're doing. Let us know if you need anything. You know, here's an offer for counseling should you need it," that would be amazing. (Bereaved family 11, 33yr female carer for father-in-law with malignancy)*

Participants noted this would enable positive feedback, as they are often not aware of how to provide this.

*I think it would be good on two levels, because sometimes there's some amazing things that happen to you. You go, "Gee, that was a really positive experience." Having the opportunity to give constructive, positive feedback to those nurses who really did make a difference, as well as those who actually did cause trauma...I'm a person that would like to be called. Other people may prefer to do it in paper, because they can think through their answer...(Bereaved family 8, 56yr female carer for mother-in-law with malignancy)*

### **Willingness to contribute to health service improvement work varies according to diagnosis, timing and role**

Perspectives on contributing to clinical governance processes varied by person (patient / family member), timing (current / bereaved) and diagnosis (malignant / non malignant). Bereaved family members were often keen to contribute in a meaningful consumer representative role.

*... be really nice to think someone could learn from this experience. Let's not replicate this. Let's do it better next time. (Bereaved family 5, 56yr female carer for mother with malignancy)*

Bereaved family members preferred ongoing roles that were mindful of time commitments and equipped to enable real change.

*I suppose I'd think, is it worth the energy, because will it make any difference? Is it just that you've gotta have a consumer on your committee, and so you have a token consumer in and if it ever actually makes a difference to what happens, I don't know (Bereaved family 4, 69yr female carer for friend with malignancy)*

The importance of considering the consumer representative role carefully for people who are bereaved was highlighted with specific noting of what are the consumer's needs and when is the right timing for their involvement?

*So I guess in terms of being involved in focus groups or in those sorts of things for people who are very distressed - how long after that would need to be, I'm not sure, I'm not sure. (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

Considering the health literacy of each participant is important if meaningful engagement and true co-design is sought.

*...before we even start to ask people to co-design that they need to have some level of literacy, they need to have some knowledge about the system because they can't help design something if they don't know how it works in the first place and they can't recognize what is good and bad care. (Bereaved family 6, 68yr female carer for brother-in-law with malignancy)*

In contrast, the majority of current family members felt unable to participate in such forums whilst actively caring for someone due to time pressures, with most open to the idea of discussing opportunities following their loved one's death.

*I couldn't like at the moment because I can't leave her for too long, so I have to get carers and that in, so it makes it a bit awkward at the moment. Yeah. Yeah maybe down the track. (Family 18, 59yr female carer for mother-in-law with non-malignant illness)*

Patients and current family members expressed more interest in participating through a one off focus group specifically discussing issues of concern to them (e.g palliative care). However, individual variation in wanting to participate in providing more formal feedback to health services, from patients, was noted.

*A worthwhile focus group, run well, for good reasons, good outcomes... of course I'd be interested. Yeah. (Patient 3, 80yr female with non-malignant illness)*

Variation was noted in relation to diagnostic group and keenness to contribute to formalised clinical governance roles. Several patients with malignant diagnoses stated this would not be of any interest to them.

*Not at the moment. At the moment, I've got too much going on. But... if you want some genuine feedback, I'm happy to provide it...No, that'd be a bit difficult for me at the moment. I've got three lovely boys, and I'm trying to live life, you know? (Patient 14, 45yr male with malignancy)*

Conversely, several patients with non-malignant diagnoses were keen to be involved in some way both with a focus on enabling improvements but also to 'give back' to the system that is providing support for them.

*Yeah. I would be quite happy to do that if there was a committee or something like that, I'm quite happy to go and contribute to that. I think with doing dialysis it's free, which is ... and it's very expensive to do, I realise that... so my attitude is I think that you should give something back.... that's what you should do. (Patient 13, 61yr female with non-malignant illness)*

### **Face to face feedback is preferred for health service improvement work**

When participants were asked to reflect on their engagement with service improvement work, individual variation in relation to how a meeting or committee representation may take place was noted. The majority of participants preferred a face-to-face format as they feel it helps to focus the mind and enable verbal and non-verbal cues from others.



*I think face to face meetings always work better than webinars. I think when all the invested people are sitting in the same space, the conversation and decision-making happens better. (Family 5, 50yr female carer for mother with malignancy)*

The fact this can be logistically difficult to arrange was acknowledged and webinars were also noted to be very useful formats.

*I think the webinar idea is terrific because you can get to all sorts of people that you wouldn't get to face-to-face. To me, in anything in this life, face-to-face is always the preferred option, always, but if you can't do that, then you take the best of the rest. (Bereaved family 1, 66yr male carer for wife with malignancy)*

Patients did also note the fact that phone meetings make it easier for them to attend as they don't have to be up, dressed and arrange transport to attend a face-to-face meeting.

*I think if you could do a teleconference, that would be easier for people who come from all different locations. For some people getting up, for me it's not such a bad thing to get up and go to a place to meet. But when you look at other people, I think a video conference is probably more suitable because people go 'oh I've got to go down do that', and not bother...Whereas in the comfort of their home, they can go, "oh yeah, I'll do that." ..Because they might have a bad day or something. (Patient 4, 54yr female with malignancy)*

Rural participants also noted the fact that remote attendance for meetings is supportive for them.

*Well, certainly, because we're regional. Remotely would be good, but then we wouldn't object to coming in to be part of something as well, so we're flexible that way. But I suppose it's very individual, too, given people's context as to what they'd be able to contribute. (Family 8, 52yr female carer for father with malignancy and bereaved carer for daughter with non-malignant illness)*

## **Discussion**

This qualitative study adds depth of understanding about how clinicians, researchers and policy makers might best embed palliative care consumer perspectives into health service development. Patients and families highlighted their need for input to be tailored to their complex and changing needs, to be supportive and individualised, mostly sought on discharge, to be cognisant of time burden (ensuring evident action and outcomes from time invested) and allow for differing preferences regarding the method of engagement (formal, informal, face to face and/or virtual).

When asked about how patients and family members would like to provide feedback about current care provision, responses remained specific to individual care experiences and a response in real-time was expected. This is important as confirms what is well stated in guidance<sup>25</sup> and recent publications,<sup>26-28</sup> but remains elusive in routine practice.<sup>29</sup> That such data needs to inform care through appropriate reporting mechanisms and response by those able to affect a change in care provision is well stated.<sup>13, 28, 30</sup> Participants noted their strong preference for an identified key person with whom they can liaise on a day-to-day basis in relation to care provision. The potential for this role to be supported through integrated nurse specialist roles and/or ward based nursing leadership is well described.<sup>30-32</sup> Collection of patient/family reported data to inform both care (identifiable data) and service improvement (deidentified data), through carefully established mechanisms to deidentify and collate available data, is an important area of innovation requiring progress.

The need to consider data collection alongside patient and family comfort to speak openly is highlighted. Our study confirms previous findings that patients with serious illness worry about repercussions from real-time feedback given their dependence on medical care.<sup>33</sup> This is important when considering implementation of outcome and experience measurement into routine service improvement work. Research involves well-established mechanisms to ensure confidentiality of data capture, which would not necessarily be present in daily clinical care. Participants noted their preference for being contacted after discharge with the offer of either survey or interview-based feedback. Contact was not helpful if made at a time where a patient's condition was unstable.

A recent systematic review aiming to better understand consumer leadership in palliative care notes the complexity of 'when', 'who' and 'how'.<sup>1</sup> This study's outcomes confirm this complexity but also provides context in relation to diagnosis from a patient perspective ('who'). The majority of patients with an advanced malignant diagnosis did not wish to participate in formalised service evaluation work. They did state they were happy to have an informal discussion (such as in this research study) that was focused and took minimal time and effort. In contrast, patients with advanced non-malignant diagnoses value contributing to formalised service evaluation work but noted a preference for targeted focus groups rather than more general improvement forums. This difference may reflect the varied prognostic trajectories of living with advanced and progressive malignancy as opposed to advanced serious illness and/or varied awareness of likely prognosis. However, this finding is important when planning for engaging consumers for health service improvement work. This study also informs an understanding of 'when' from the family member perspective. Family members providing care are stressed, time poor and feel unable to contribute to service improvement work. However, all expressed their willingness to discuss this option when bereaved.

Patients with advanced non-malignant diagnoses and bereaved family members ('who') are best positioned to contribute within formalised and ongoing roles ('how'). Patients with advanced malignant diagnoses and family members currently caring for loved ones are best positioned to contribute to immediate outcome and experience measures and one-off discussions to inform practice, policy or research.

### **Strengths and limitations**

Study strengths include the engagement of consumers in co-designing the research protocol,<sup>14</sup> defining the sampling approach, interviewing and data analysis. Co-design enabled broad and representative sampling with similar numbers of people with advanced malignant and non-malignant illness participating. Whilst this doesn't represent the 'usual' specialist palliative care population, it does represent the true population of people with palliative care needs,<sup>34</sup> and particularly so within the acute hospital setting.<sup>30, 33</sup> A study limitation includes that views of people from culturally and linguistically diverse backgrounds, and Indigenous Australians are underrepresented. In addition, the sample of bereaved carers was biased to those with postgraduate education. It is possible the question route led participants to reflect on current care rather than broader health service improvement and this may have impacted outcomes. It is also possible participants had differing understandings of clinical governance and it may have been helpful to define this at interview commencement for all. Finally, statements made about differences in perspectives from people living with malignant as opposed to non-malignant illness are based on a subset of the patient sample only and therefore caution should be used when generalising these recommendations due to the smaller sample size.

### **Recommendations for future practice**

Recommendations for future practice centre around three key areas:

1. Embed mechanisms for real-time feedback that impacts immediate care provision through targeted outcome and experience measurement relevant to those with advanced serious illness. Integrating these mechanisms is needed: at each ward or department level; to be integrated into routine clinical care practices informing interdisciplinary care planning and provision; to be provided in a variety of formats; and to enable the option for identified or deidentified data capture in accordance with patient and carer preference. Ensuring clinical responses are supportive (and not defensive) will be an essential component of this work;
2. Establish a variety of mechanisms for feedback post-discharge with consideration of timing. Feedback needs to align with a time of illness stability or after a respectful period post-bereavement and ought to provide an opportunity for both interview

and/or survey format. Enabling support in real-time to accompany this process allows patients and family members to view this as useful and not tokenistic;

3. Enable a variety of approaches to enable meaningful and targeted representative roles for patients with advanced non-malignant serious illnesses and bereaved family members for longer term input for health service improvement.

### **Recommendations for future research**

Key questions for additional research have been highlighted throughout this study and centre around two key areas:

1. Mechanism of feedback – the question of ‘how to’, with variation noted to date (paper, online and interview based), and the question of ‘who’ (clinician, volunteer, health care worker outside of the care team
2. Timing of feedback – with a particular need to better understand the impact of, and comfort with, provision of real-time feedback that can be used to contribute to care provision for the individual consumer. Enabling this in a way that does not rely on ‘rating’ care provision may feel more possible for patients and family members who are dependent on the clinical care team and fear reprisal if they criticise care. However, this warrants further investigation.

### **Conclusions**

Substantial reform is required to improve care and outcomes for inpatients with palliative care needs.<sup>30, 33</sup> Developing a framework for involving palliative care consumers in informing improvement work will be critical to ensuring the reform process remains aligned with patient and family priorities.<sup>30, 33</sup> However, enabling meaningful input and impact requires careful consideration of the unique requirements of this population. Embedding tailored outcome and experience measures to inform real-time care provision coupled with focused opportunities for input may enable real and sustained improvements in inpatient care provision for people with palliative care needs, founded in what matters most for people requiring this care.

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conceptualisation of this study and research protocol development. CV led the recruitment, conducted all interviews and managed the transcription and data extraction processes. CV and TL developed the coding structure used to inform the initial data analysis. CV, TL and JP participated in consensus discussions about data analysis. All authors contributed to the writing of this manuscript.

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The authors declare that there is no conflict of interest.

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### **Data management and sharing**

Raw data are contained within this manuscript in the form of participant quotes and also available within Appendix 1. The corresponding author is available to contact for further information. However, further data about each specific quote cannot be provided due to the risk of re-identifying the participants involved.

## References

1. Scholz B, Bevan A, Georgousopoulou E, et al. Consumer and carer leadership in palliative care academia and practice: A systematic review with narrative synthesis. *Palliative Medicine* 2019; 33: 959-968.
2. Rumbold B and Aoun SM. Palliative and End-of-Life Care Service Models: To What Extent Are Consumer Perspectives Considered? *Healthcare* 2021; 9: 1286.
3. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations* 2014; 17: 637-650.
4. Consumers Health Forum of Australia. *Shifting Gears — Consumers Transforming Health. A White Paper*. 2018. Canberra, Australia.
5. Wales CR, Lababedi JA, Coles A, et al. Consumer representative experiences of partnership with health workers in Australia. *Patient Experience Journal* 2021; 8: 64-78.
6. Consumer Health Forum of Australia. "Unique and essential": A review of the role of consumer representatives in health decision-making Deakin ACT: Consumer Health Forum of Australia. 2015
7. Ball S, Amelia Harshfield, Asha Carpenter, et al. *Patient and public involvement in research: Enabling meaningful contributions*. 2019. Santa Monica, CA. [https://www.rand.org/pubs/research\\_reports/RR2678.html](https://www.rand.org/pubs/research_reports/RR2678.html).
8. Daveson BA, de Wolf-Linder S, Witt J, et al. Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative medicine* 2015; 29: 939-949.
9. Oliver K, Kothari A and Mays N. The dark side of coproduction: do the costs outweigh the benefits for health research? *Health Research Policy and Systems* 2019; 17: 33.
10. Research NifH. National Institute for Health Research Glossary, <https://www.nihr.ac.uk/glossary> (2022, accessed March 21 2022).
11. Cancer Australia and Cancer Voices Australia. *National Framework for Consumer Involvement in Cancer Control*. 2011. Cancer Australia, Canberra, ACT.
12. Czuba KJ, Coomarasamy C, Siegert RJ, et al. Measuring health consumers' engagement at the governance level: development and validation of the Middlemore Consumer Engagement Questionnaire. *New Zealand Medical Journal* 2022; 135: 1175-8716.
13. Viridun C, Lockett T, Davidson P, et al. Hospital patients' perspectives on what is essential to enable optimal palliative care: a qualitative study. *Palliative Medicine* 2020; 34 1402-1415. DOI: <https://doi.org/10.1177/0269216320947570>.
14. Viridun C, Lockett T, Gilmore I, et al. Involving consumers with palliative care needs and their families in research: A case study. *Collegian* 2019; 26: 645-650.
15. The University of Edinburgh. SPiCT, <https://www.spict.org.uk/> (accessed August 16 2018).
16. Abernethy AP, Shelby-James T, Fazekas BS, et al. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliative Care* 2005; 4: 7.
17. Malterud K. Qualitative research: standards, challenges, and guidelines. *The Lancet* 2001; 358: 483-488.
18. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007; 19: 349-357.
19. Irvine A. Duration, dominance and depth in telephone and face-to-face interviews: A comparative exploration. *International Journal of Qualitative Methods* 2011; 10: 202-220.
20. Novick G. Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health* 2008; 31: 391-398.
21. Bradley EH, Curry LA and Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Services Research* 2007; 42: 1758-1772.

22. Boyatzis RE. *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications, 1998.
23. Green J, Willis K, Hughes E, et al. Generating best evidence from qualitative research: the role of data analysis. *Australian & New Zealand Journal of Public Health* 2007; 31: 545-550.
24. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine* 2014; 89: 1245-1251.
25. Bausewein C, Daveson BA, Currow DC, et al. EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services – Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement. *Palliative Medicine* 2016; 30: 6-22. DOI: 10.1177/0269216315589898.
26. Antunes B, Harding R and Higginson IJ. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliative Medicine* 2014; 28: 158-175.
27. Antunes B, Rodrigues PP, Higginson IJ, et al. Outcome measurement—a scoping review of the literature and future developments in palliative care clinical practice. *Annals of Palliative Medicine* 2018; 7: S196-S206.
28. Pinto C, Bristowe K, Witt J, et al. Perspectives of patients, family caregivers and health professionals on the use of outcome measures in palliative care and lessons for implementation: a multi-method qualitative study. *Annals of Palliative Medicine* 2018; 7: S137-S150.
29. Antunes B and Bausewein C. Challenging but Beneficial: Using Outcome Measurement in Routine Care for Patients With Advanced Disease. *Annals of Palliative Medicine* 2018; 7: S135-S136.
30. Virdun C, Lockett T, Davidson P, et al. Strengthening palliative care in the hospital setting: A co-design study *BMJ Supportive and Palliative Care* 2020; In Press.
31. Australian College of Nursing (ACN). *A New Horizon for Health Services: Optimising Advanced Practice Nursing—A White Paper by ACN 2019*. 2019. ACN, Canberra.
32. Brandis S, McPhail, R., Fitzgerald, A., Avery, M., Fisher, R., & Booth, J. The emergence of new kinds of professional work within the health sector. In: A. Wilkinson, D. Hislop & C. Coupland, (ed) *Perspectives on Contemporary Professional Work: Challenges and Experiences*. Elgar, Cheltenham, 2015.
33. Virdun C. *Optimising care for People with palliative care needs, and their families, in the Australian hospital setting: the OPAL Project*. University of Technology Sydney, 2021.
34. Australian Government Department of Health. *National Palliative Care Strategy 2018*. 2018. Australia.