FEEDBACK-FUELLED ADAPTATION: EMBRACING CHALLENGES, INSPIRING INNOVATION

Annette Vickery [1], Toni Rice [1]
1. Palliative Care Australia, Canberra, ACT, Australia

KEYWORDS

Please list a minimum of three (3) keywords

1. Lived Experience Input
2. Collaborative Collaborative creation
3. Trust-building Engagement
4. Innovative Solutions
5. Open-minded Adaptation

EXECUTIVE SUMMARY (100 words maximum)

Palliative Care Australia values are Trusted, Collaborative and Bold; we are dedicated to enhancing paediatric palliative care by prioritizing the voice of lived experiences. In the "Shaping the Future of Paediatric Palliative Care Project," we authentically collaboratively created with families and young people, to guide the project activities. Rooted in our Paediatric Palliative Care National Action Plan where we engaged over 150 stakeholders, which included parents, carers and young people, we built trust through genuine collaborative creation, we adapted to feedback and recognised that true collaboration demands putting aside any preconceptions. This paper describes the requirements and rewards of this approach.

INTRODUCTION

Our paper underscores the pivotal role of collaborative creation in advancing family-centred care, emphasising its significant nature. Collaborative creation involves engaging end-users, from initiation in product design to ensure it caters to their needs. We highlight the depth of stakeholder engagement, advocating for genuine empowerment and attentive listening to family voices. This approach can bring significant shifts in perception and direction. We have found that investing in listening to families greatly enriches resources, as evidenced in our project. Despite encountering challenges, such as understanding family narratives and pinpointing effective strategies, our overarching aim remains clear: to empower families in improving outcomes for other families, recognising the demanding yet fulfilling nature of this project.

HIGHLIGHTS

1. Empowering Families: Deep stakeholder engagement recognising challenges and rewards.
2. Values-Driven: Trust, Collaborate, Bold; collabrative creation and consumer-led enhance palliative care.
3. Resource Success: Increased engagement reflects meeting consumer information needs

METHODOLOGY/ PROCESS

In our project, we structured our approach around Driscoll's 'What, So What, Now What?' framework by first identifying the current state of paediatric palliative care (What), analysing its significance and implications (So What), and determining actionable steps for improvement (Now What). This framework provided a structured and systematic approach to guide our research and development process, ensuring that our efforts were focused on meaningful outcomes while maintaining a commitment to ethical practice and consumer engagement.

Ethical Engagement and Dialogue:

Following NHMRC guidelines, we conducted stakeholder meetings, focus groups, and surveys with full transparency, formal ethics approval and informed consent, adhering to principles of respect for autonomy and equitable, supported participation. These interactions facilitated open dialogue and allowed us to ask questions to uncover valuable insights into their experiences and needs, whilst ensuring stakeholders were provided with comprehensive information and support, making their involvement meaningful.

Prior to inviting consumers to participate in project activities the team met with them on an individual basis. This approach enabled the team to understand the consumers individual experience and areas of interest and targeting their engagement thus not placing too much demand on the consumer.
Early on in the process the team identified that whilst consumers had a powerful story to tell, in doing so often brought back painful memories. The need to support consumers who participated in the project through formal support mechanisms was essential. We were not sure how many consumers used this service, but they appreciated that the support was available to them if needed.

Empowerment and Collaboration in Consumer-Centric Practice

Throughout our project, we prioritised the voices of consumers and committed budget and resources to ensure the value and sustainability of this. Consumers were not only actively involved in decision-making processes but were also integral to shaping the direction and outcomes of the project. Roles for individuals with lived experience, included storytellers, advisors, and partners. Their perspectives were central to every aspect, guiding discussions, shaping strategies, and influencing the development of resources. This approach ensured that the solutions we created were not only informed by their experiences but also tailored to their diverse needs and preferences, fostering a sense of ownership and empowerment among stakeholders .

Integrated Methodology:

By integrating qualitative methods such as interviews and focus groups with quantitative data analysis, we ensured a comprehensive research approach. However, limitations arose in quantitative analysis due to the absence of a specific data collection tool for paediatric palliative care. Despite this challenge, our commitment to integrity and rigorous research remained unwavering, guiding our approach throughout the project.

RESULTS/ OUTCOMES

In our project, 76 consumers, including mothers, fathers, carers, siblings, young people and a volunteer participated in various activities such as podcasts, webinars, written resources, videos, and parent training materials. These individuals generously contributed their invaluable insights and perspectives to shape the development of our resources. Through collaborative efforts, we co-designed a total of 38 resources, including two consumer-led parent training resources and 10 personal stories. We are pleased to report that our resources have not only been extensively downloaded but also ordered, indicating their value and relevance to the wider community. This level of engagement underscores the success of our approach in meeting the diverse needs of consumers and stakeholders in paediatric palliative care. Families found their involvement to be not just productive, but also therapeutic, offering a sense of empowerment and healing throughout the process.

"I feel privileged that in my own grief, I'm in a place where I can share with and help others"– **family member**
"I felt valued and that our voices were influential" – **family member**
"Working with PCA has been the highlight of my career"– **family member**
"There were robust discussions with consumers having the leading voice, it was empowering" – **family member.**
"I'm so privileged to be part of this, consumers were seen and recognised. The experience of being involved in this study was very unique"– **family member.**
"This was a true collaboration" – consumers were equal and respected – **family member**.

CONCLUSION

In navigating the complex space that is paediatric palliative care, our journey has been guided by a commitment to collaboration, trust-building, and open-minded adaptation. By prioritising the voices of lived experiences and embracing a values-driven approach, we have fostered empowerment among families and achieved innovative solutions. Through genuine collaborative creation efforts and consumer-led initiatives, we have witnessed the tangible success of our resources in meeting consumer needs. As we reflect on our methodology, we recognise the importance of ethical engagement, dialogue, and consumer-centric practice in driving meaningful outcomes. Moving forward, we remain dedicated to embracing challenges, inspiring innovation, and continuing to shape the future of paediatric palliative care.

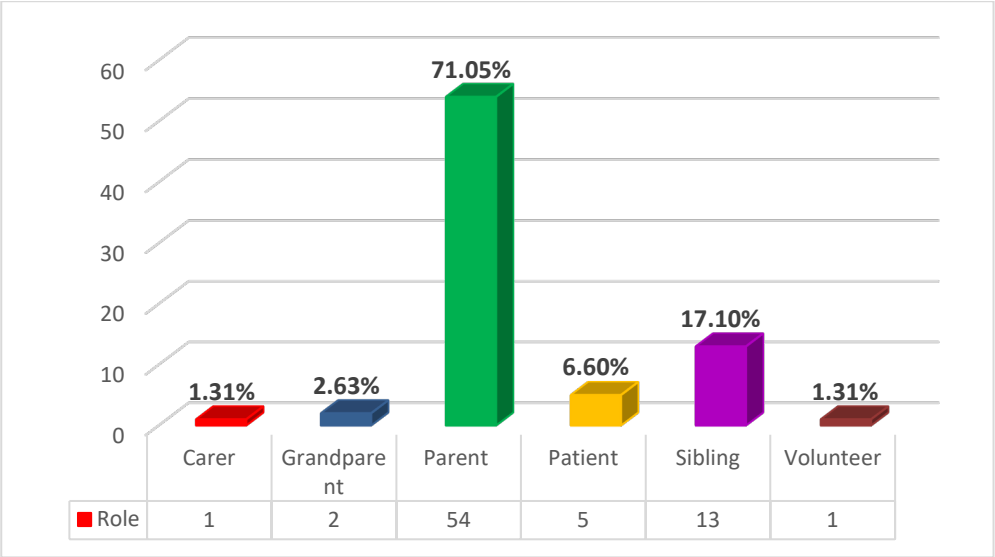


Figure 1: Project Stakeholder - Role in Paediatric Palliative Care

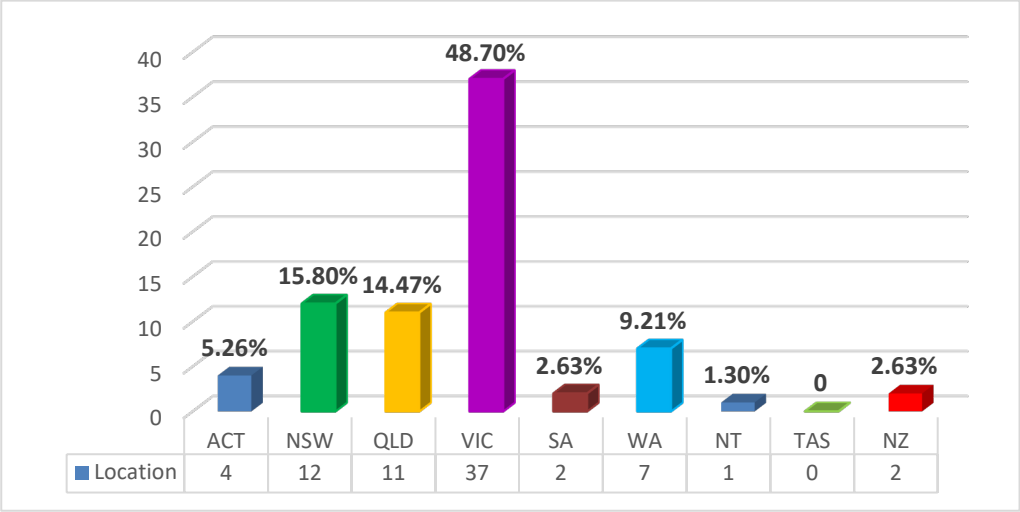


Figure 2: Stakeholder Participation – Geographical Breakdown

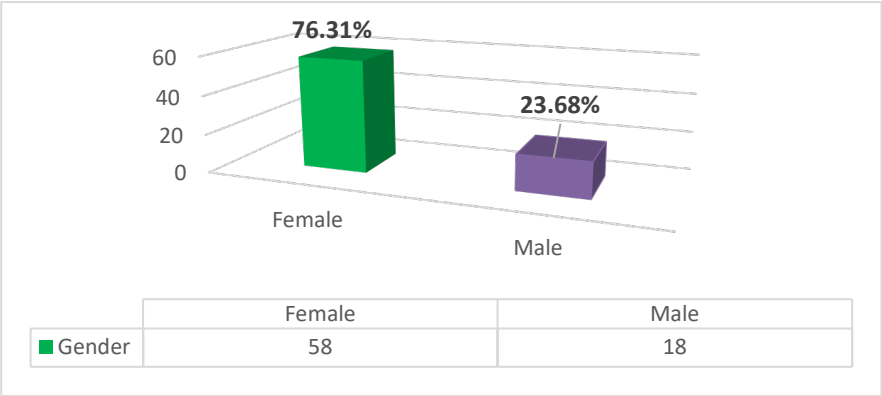


Figure 3: Project Stakeholder – Identified Gender

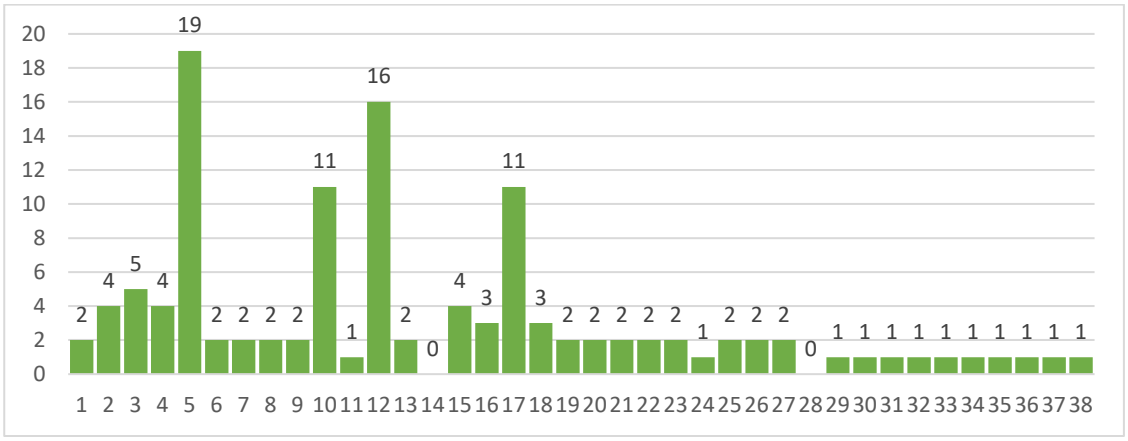


Figure 4: Number of consumers involved in each resource (Average of 3 consumers per resource)

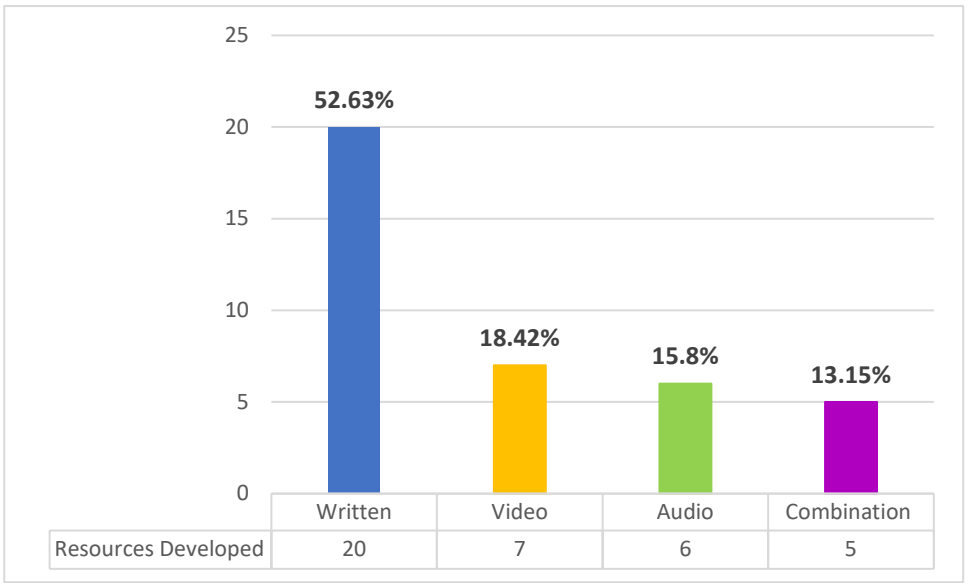


Figure 5: Resource format