

Partnership with the Homeless Community: A Shared Path to Understanding

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Te Ārai
Palliative Care & End of Life Research Group

Overview

- Who are we?
- Why is this research important?
- How did we do it?
- What did we learn?
- What are we doing differently now?



Who are we?

- Te Arai Palliative Care and End of Life research Group
- Bicultural approach to research
- Focusing on partnership, participation and protection with Māori
- Guided by Te Tiriti o Waitangi
- Social justice and equity in palliative care

www.tearairesearchgroup.net



Aotearoa New Zealand

- Diverse population of 5.1 million people
- 2.3% experience “severe housing deprivation”
- Māori experience significant health disparities
- Largest city is Auckland



Why is this research important?

Benefits being in hospital

- Feeling safe and being cared for

Not everyone has

- choice
- family to care for them
- financial and social resource
- a warm dry home



- Robinson J, Gott M, Frey R, Gardiner C, Ingleton C. Predictors of patient-related benefit, burden and feeling safe in relation to hospital admissions in palliative care: A cross-sectional survey. *Palliative Medicine*. 2017;32(1):167-171. doi:[10.1177/0269216317731991](https://doi.org/10.1177/0269216317731991)
- Robinson J, Gott M, Gardiner C, Ingleton C. A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliat Med*. 2015 Sep;29(8):703-10. doi: 10.1177/0269216315575841. Epub 2015 Mar 13. PMID: 25769983.

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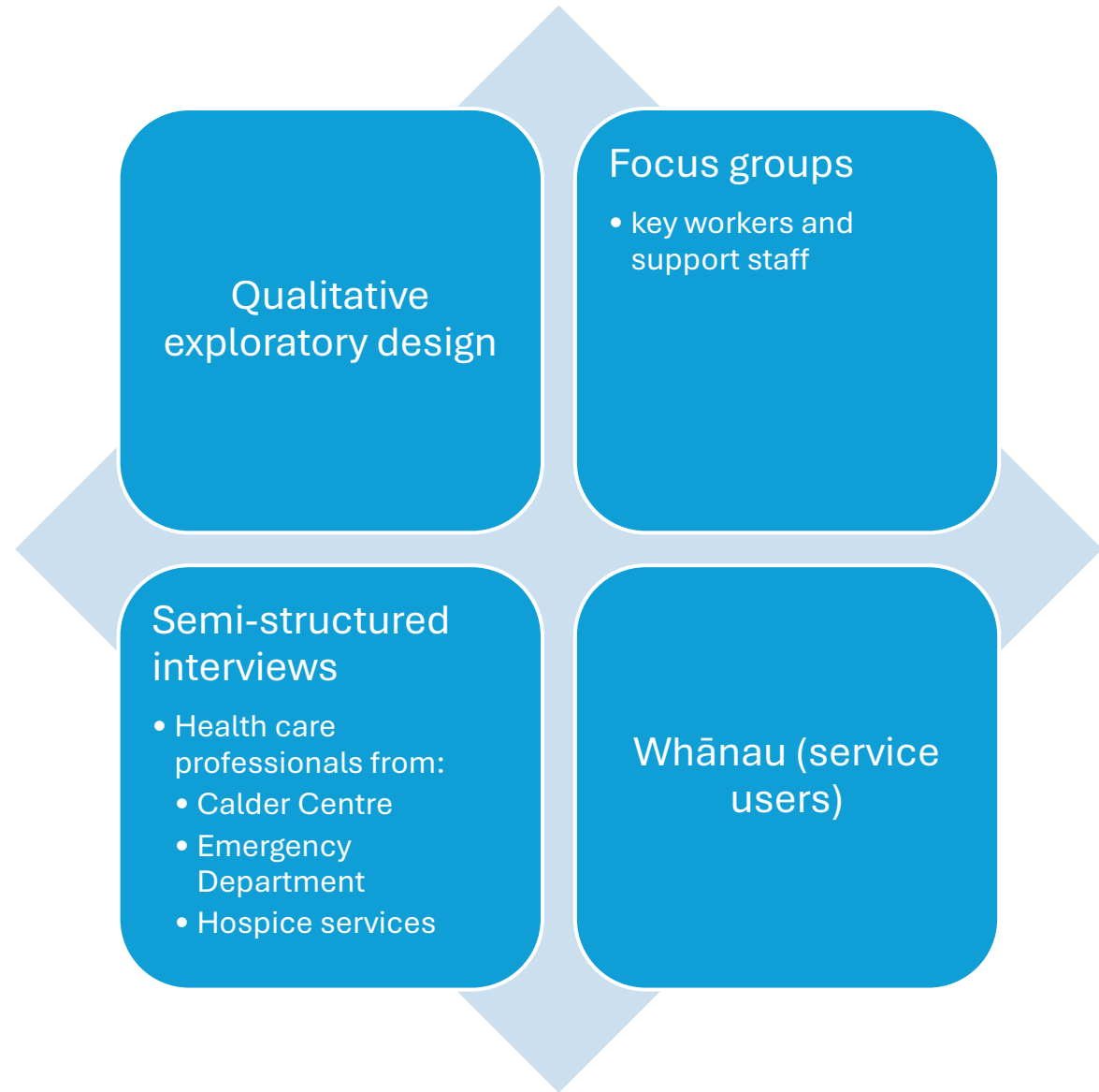


How did we do it?

- Created a relationship
 - Visited and listened
 - Provided opportunities to engage and brought kai (food)
 - Shared who we were and listened to who they were
 - Acknowledge and ask about their expertise and knowledge
- Involved them in the generation of research ideas and grant writing



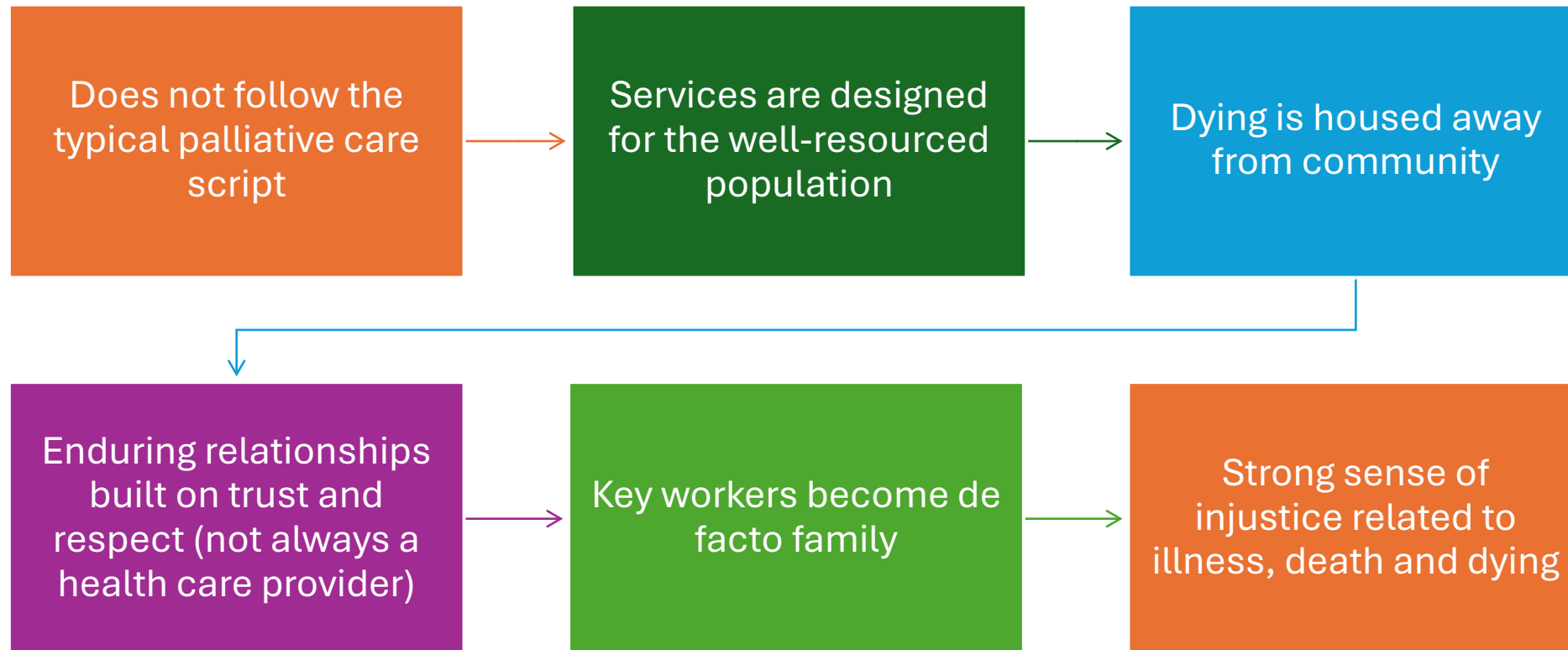
How did we do it?



Some worked....others not so much



Key findings



Street whānau

They know what they need (not always healthcare)

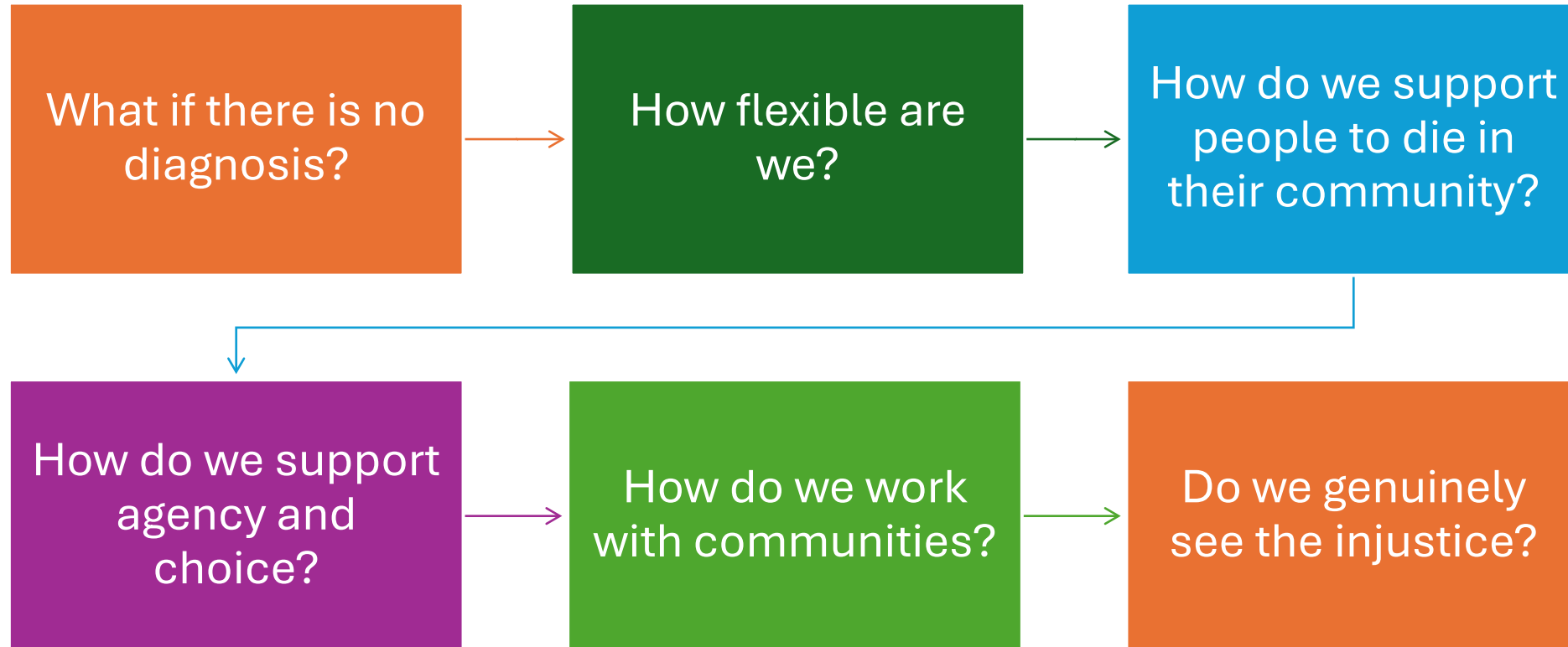
Demonstrating agency and making choices all the time

Choosing not to go to hospital even when acutely unwell

Trusting people with the traumatic stories

Difficulties imagining what life or death might be like

Questions for palliative care...



What did we learn?

- Genuine partnership is essential BEFORE the research starts
- Be flexible and be guided by the participants
- Use different data collection methods and always take kai (food)
- Take a strength-based approach



What did we learn?

Integrate a trauma informed approach throughout the research process

- Consider the impact of trauma as people share their stories
- We don't need to know their story, don't force it (retelling can cause more trauma)
- Find a safe space to engage – usually their place not ours
- Researchers with lived experience are valuable to the collection and analysis of data
- Applying a cultural lens to data interpretation and analysis to ensure that the meanings derived are contextually accurate and appropriate



What are we doing now?

- Legacy based planning (not ACP)
- Using art to express feelings about legacy
 - How do I want to be remembered?
 - What do I want to leave behind?
- Co-design with service users
 - How do I want to have the conversations?
 - Where will I record it and how will I share it?
 - Use of an illustrator



How are we doing it now?

- Participatory co-design approach – frequent contact with participants over time builds trust and connection
- Involve someone from the community in the research team and pay them!
- Art based methods can:
 - be less threatening for some people
 - create a safe space (especially if the space you use is theirs already – we were the guests)
 - be transformative for people who often don't have a voice
- Ethics approvals can be challenging – do it step by step which supports an iterative research process



Thank you
and come
visit us
sometime 😊

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