

Equity at the end of life

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Approaches to death
and dying reveal much
of the attitude of
society as a whole.

Cicely Saunders



1. Equity of access to hospice and specialist palliative care
2. Equivalent experience of palliative care regardless of setting of care
3. Equitable opportunity for people to achieve the end of life they aspire to

Reflections on equity concerns for Māori whānau

Palliative care

Palliative care is care for people of all ages with a life-limiting condition.

No matter who we are, no matter what our background, we all eventually face death and dying. Palliative and end of life care provides people with humane and dignified support and services as they face a life limiting condition. This care is essential.

Palliative care in New Zealand aims to:

- optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
- support the individual's family, whānau and other caregivers where needed into bereavement.

'Specialist' and 'primary' palliative care

**Specialist
palliative care**

**Primary
palliative care**

Family/whānau

Community

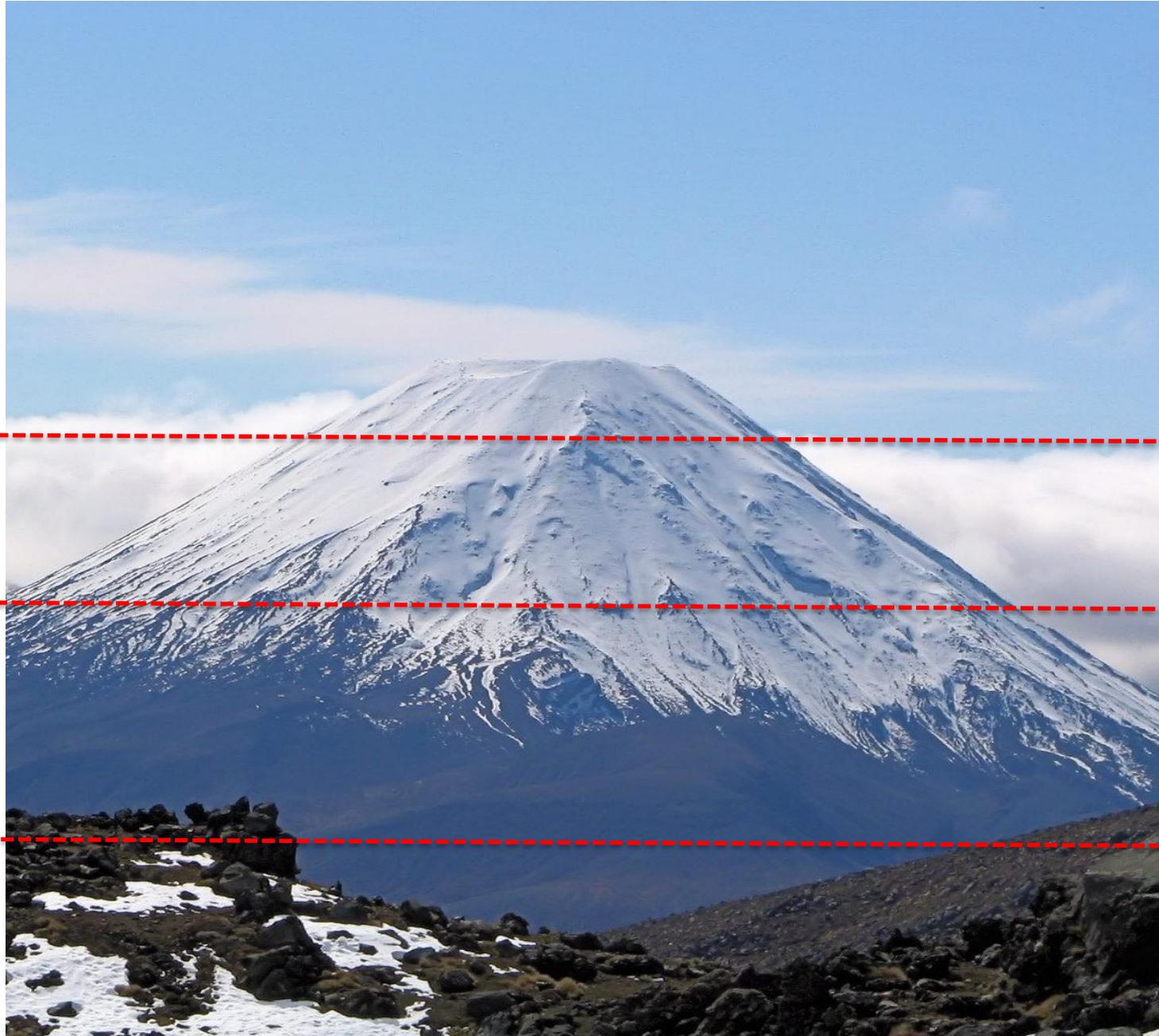
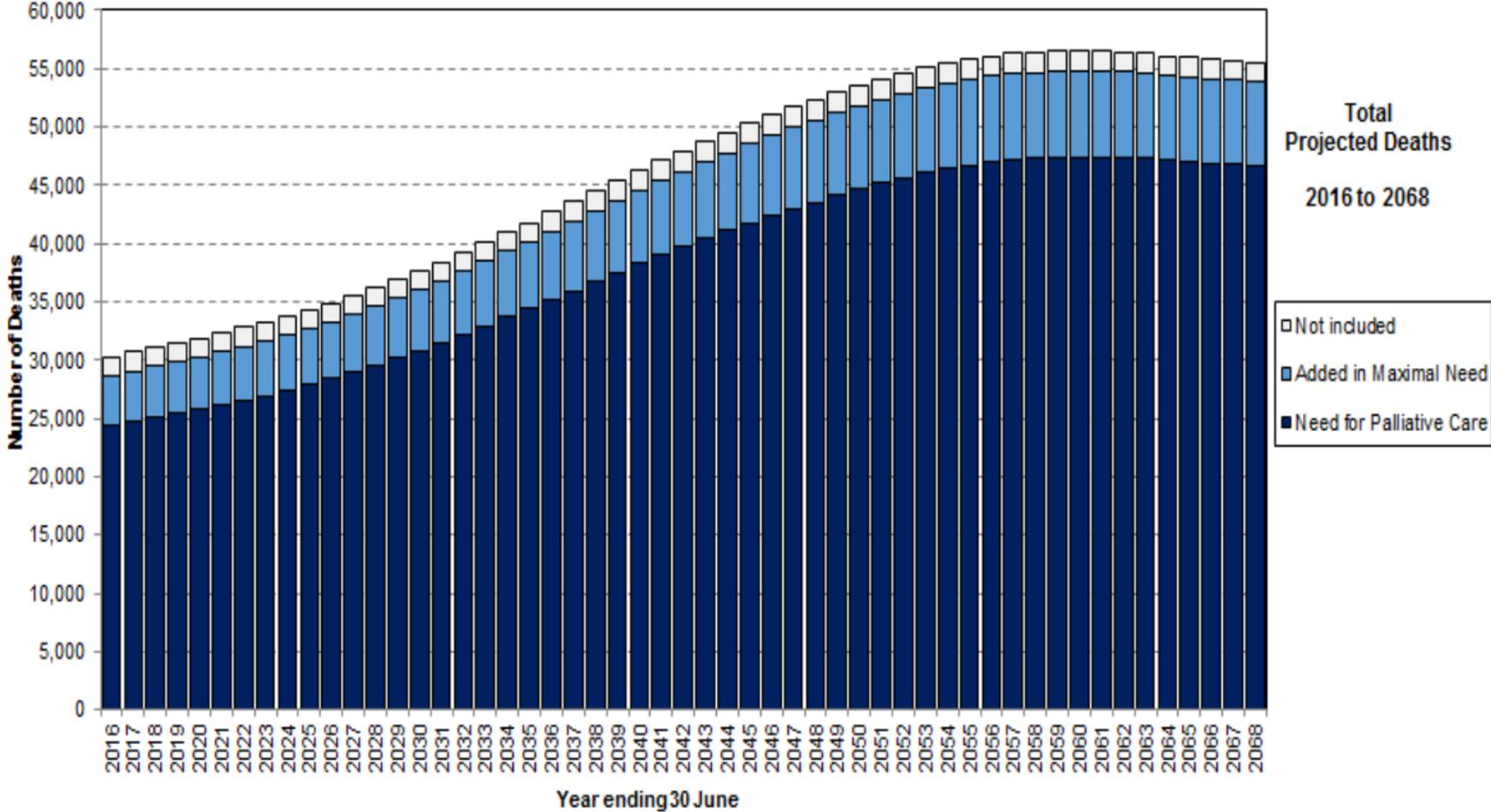


Figure 3: Projected need for palliative care in New Zealand, 2016–2068



1. Equity of access to hospice

1/3rd of people dying with palliative care need in NZ receive some level of service from hospice, including 70% of those with a cancer diagnosis.

Of these, 24% die in hospice IPU, 26% in ARC, 34% at home, and 13% in hospital.

Consistent (mostly international) evidence that some groups of people are less likely to receive hospice/specialist palliative care.....but there is very little evidence this is due to lower need for specialist palliative care services.

Less likely to access hospice/SPC

- People with conditions other than cancer
- People aged >80 years
- Indigenous people
- Black and ethnic minority people
- People living in areas of deprivation
- Homeless and vulnerably housed people
- People living in rural areas
- Single/widowed/divorced people
- People with intellectual disabilities
- People in prison

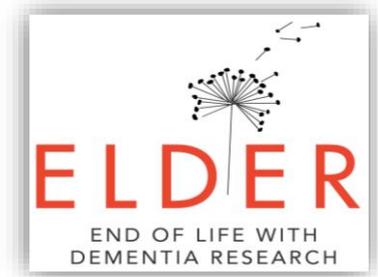


People with serious and persistent mental illness are 3.5 times less likely to receive specialist palliative services compared to the general population from the Capital and Coast District Health Board.

(Butler and O'Brien, 2018)

Equity of access to hospice in Aged Care

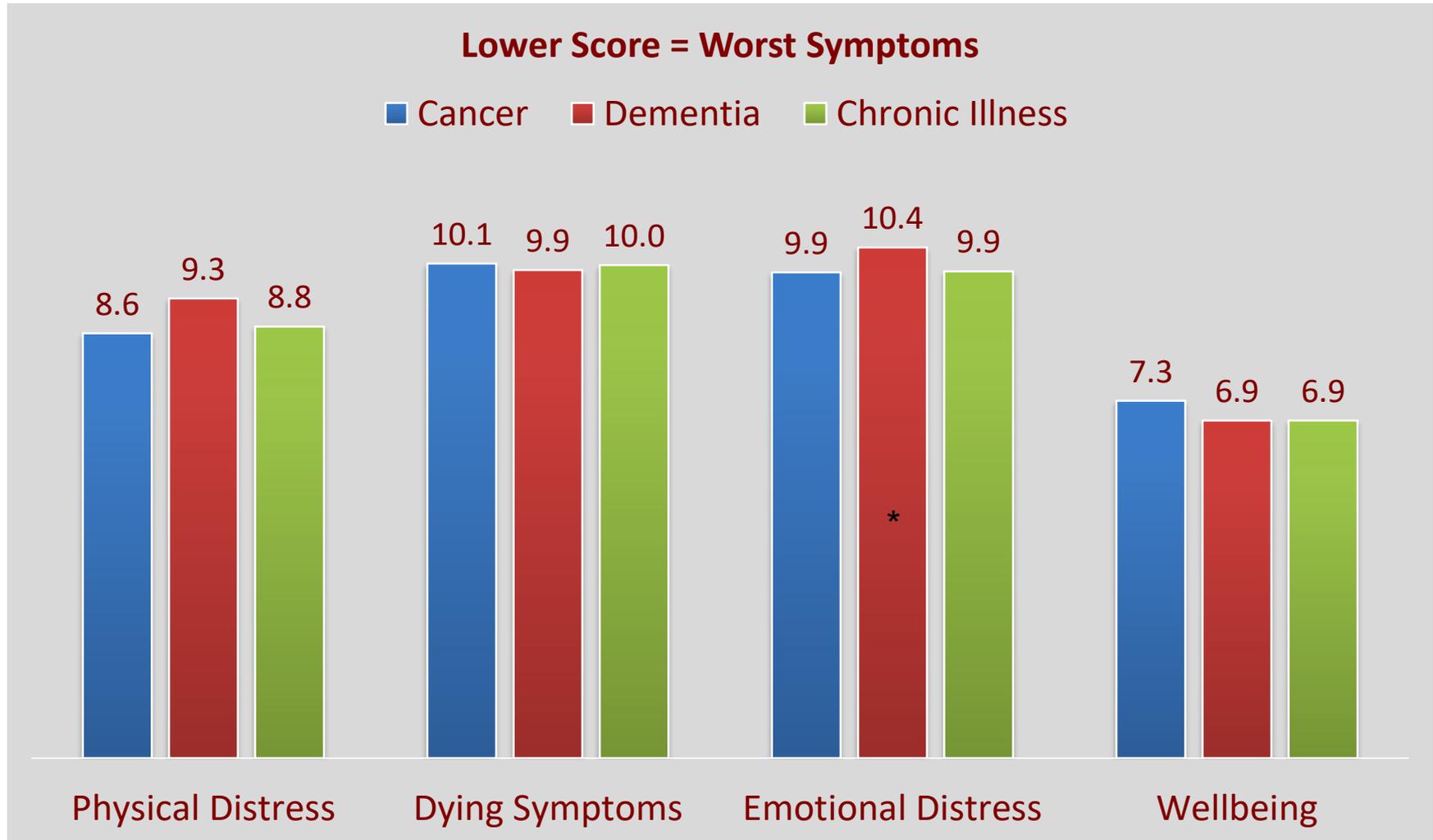
Michal Boyd, Rosemary Frey, Deborah Balmer and Sue Foster



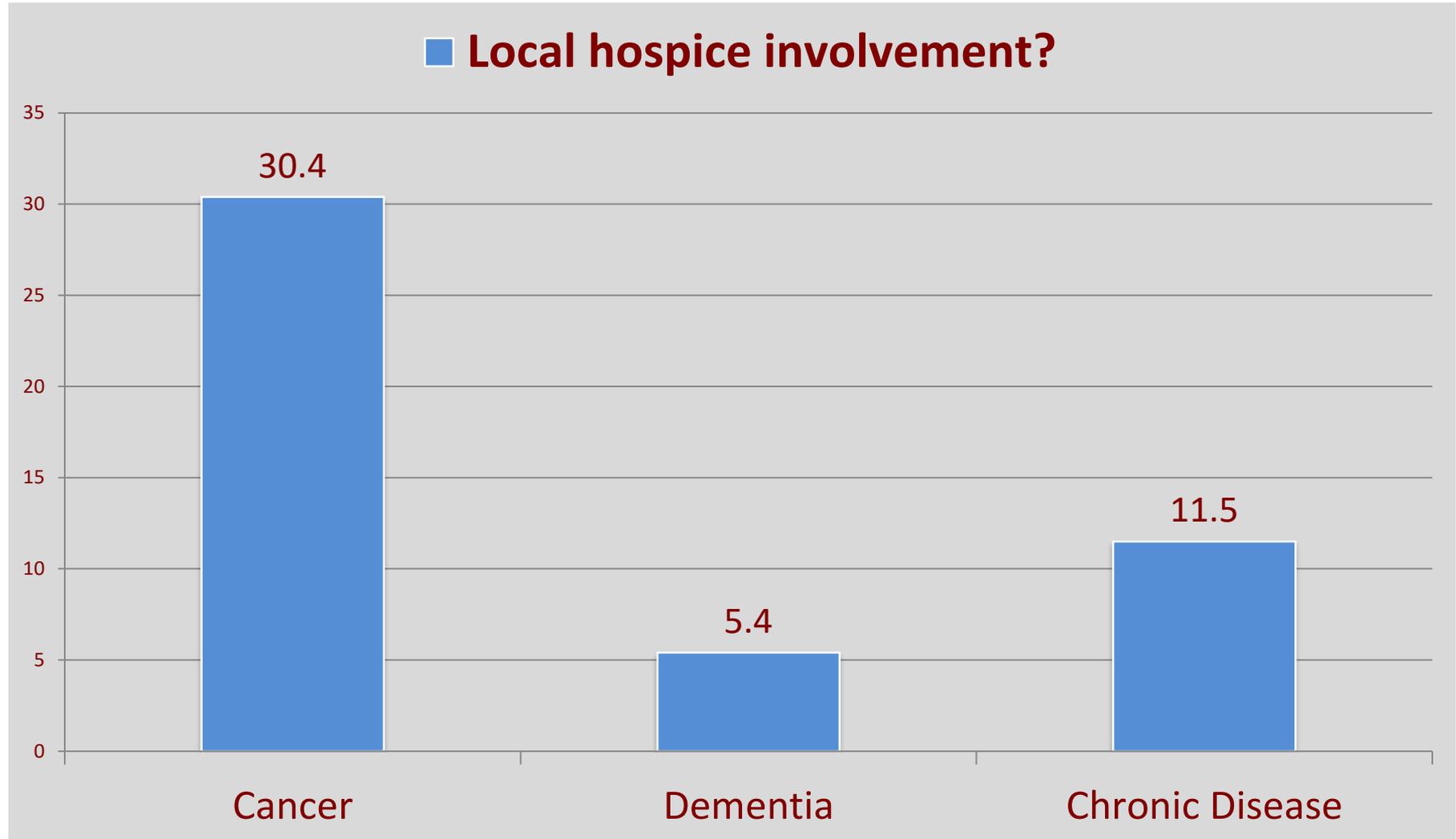
- **Aim:** to investigate quality of dying in Aged Residential Care in NZ
- 286 deaths from a representative sample of Aged Care facilities across New Zealand



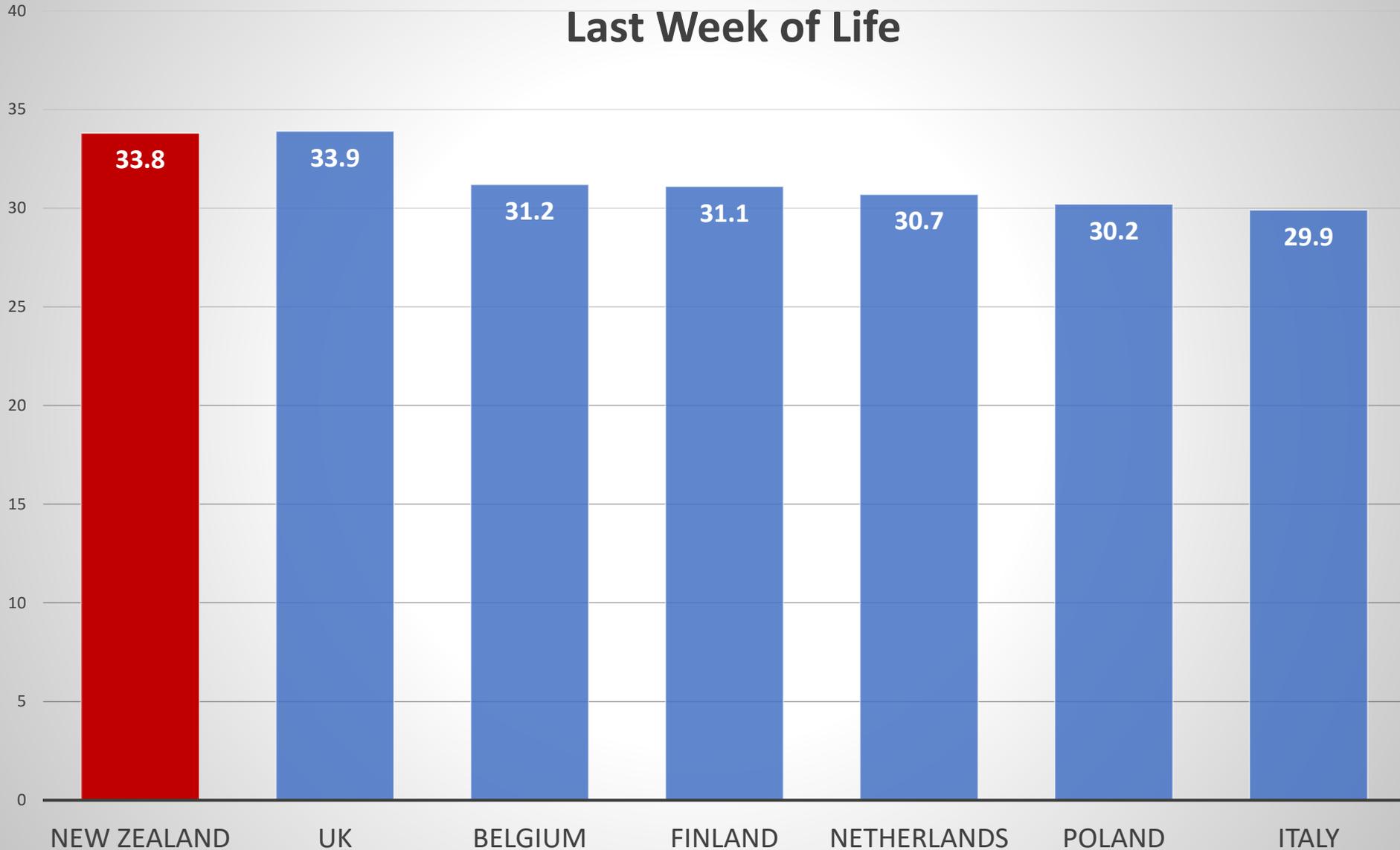
Symptoms in the last week of Life



Hospice Support: % by primary diagnosis



International Comparison of ARC Quality of Death Last Week of Life



Smets...Van Den Block (2018). Palliative Medicine 32(9), 1487-1497; Boyd et al. In press.

“Aged Care have a 1:30 nurse-to-patient ratio - a hospital has a 1:6 ratio and a hospice a 1:3 ratio – how is that fair?” (Michal Boyd)

Summary

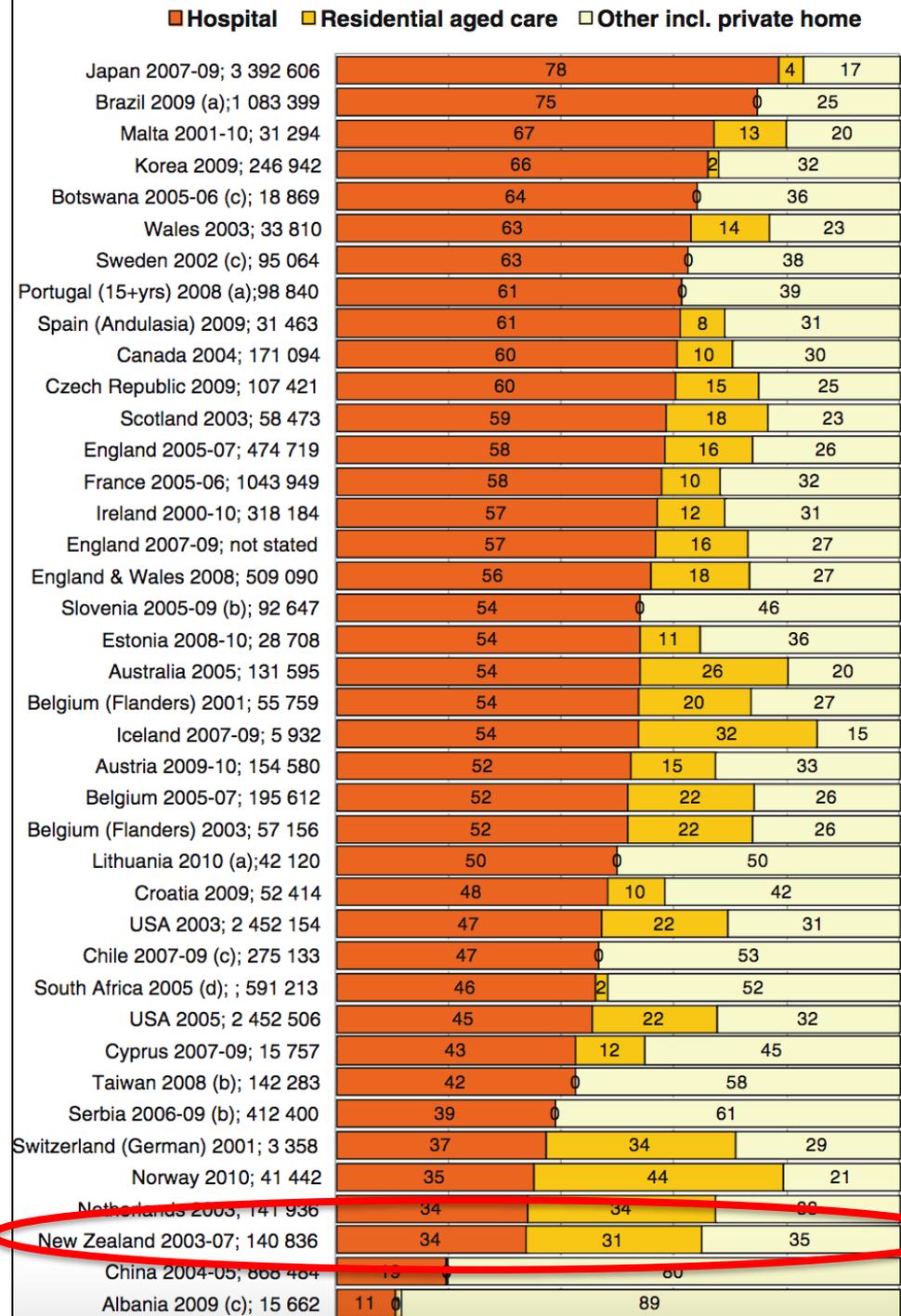
- Overall people who receive hospice services report high levels of satisfaction
- But there are significant inequities in access within a context where hospices face significant funding challenges and rapidly increasing demand
- Need new models of hospice care that spread the benefits of specialist expertise equitably, ensure most 'complex' are prioritised for specialist care, and support good relationships, and reciprocal learning, with other providers



1. Equity of access to hospice
- 2. Equivalent experience of palliative care regardless of setting of care**
3. Equitable opportunity for people to achieve the end of life they aspire to

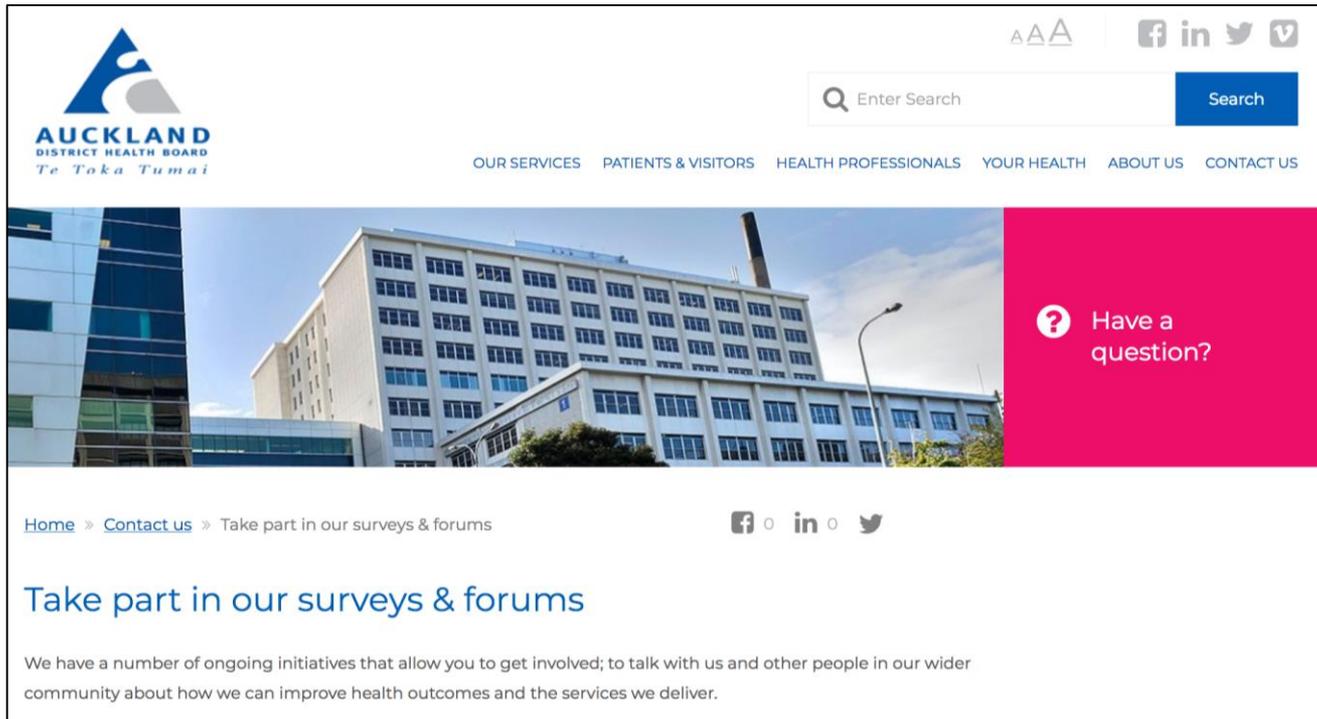
In NZ approx:

- One third of deaths are in public hospitals
- One third in Aged Care
- One quarter in private homes
- 7% in hospice IPU



Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2013). Where do people die? An international comparison. *International Journal of Public Health, 58*(2), 257-267

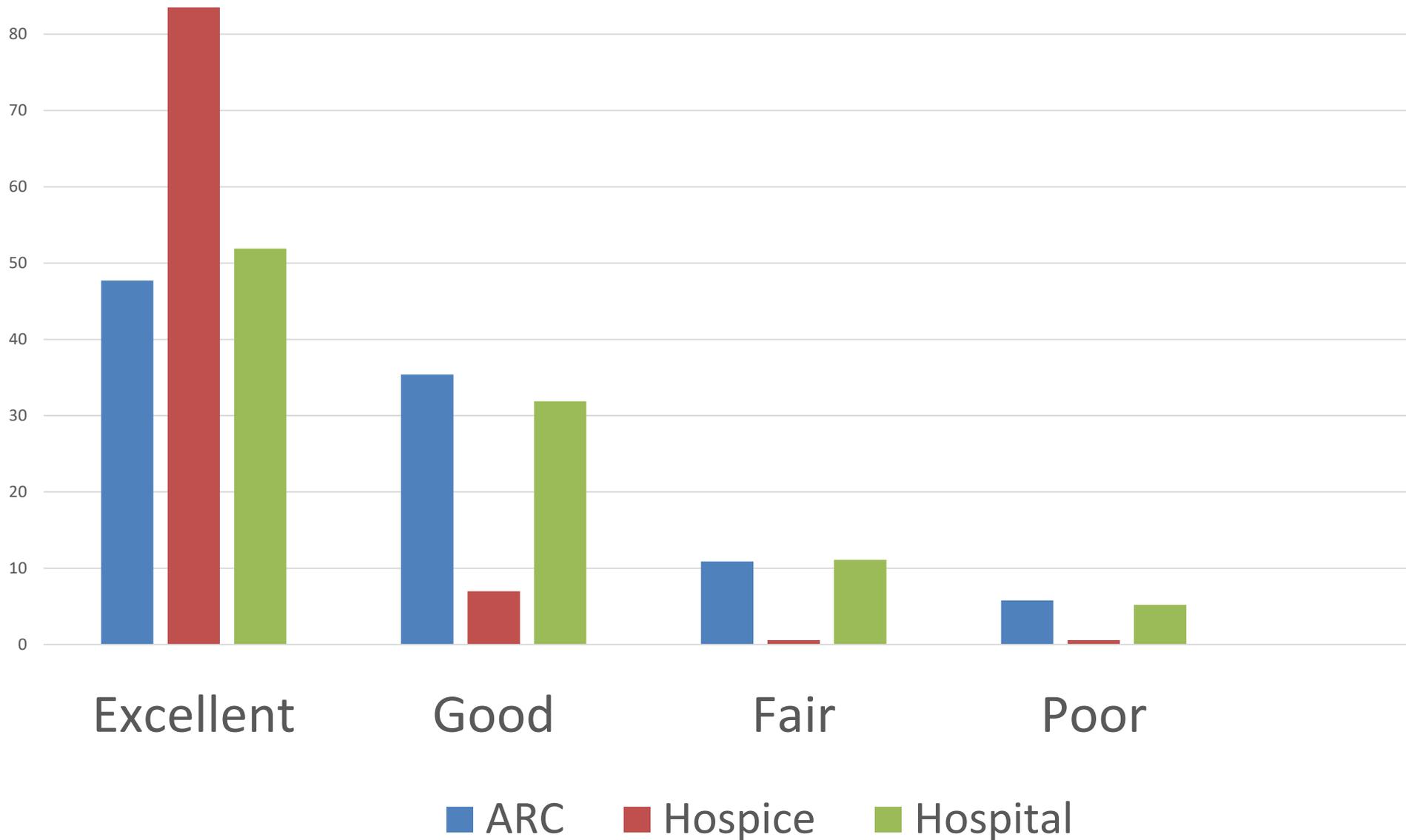
Views of Informal Carers Survey (VOICES)



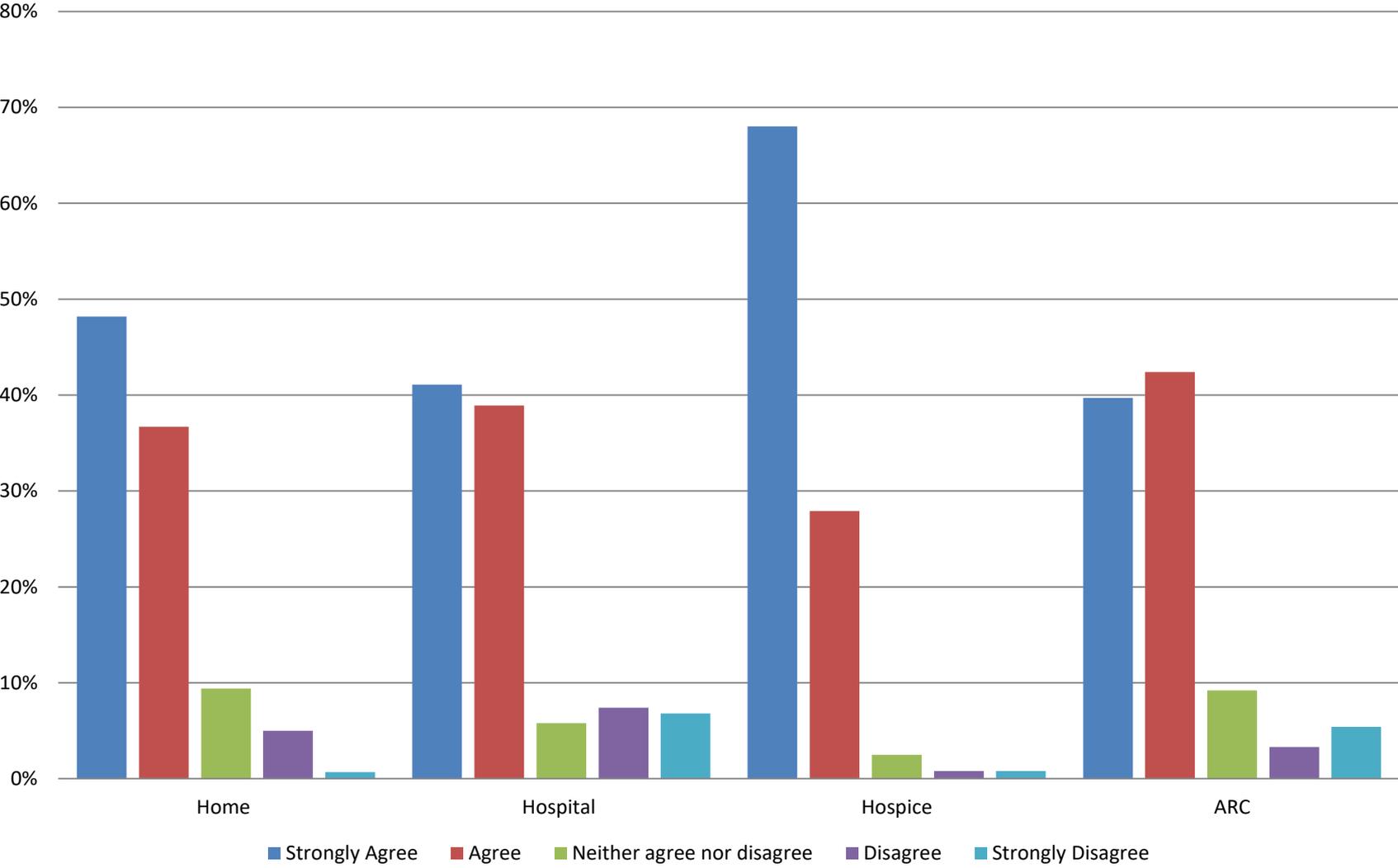
The screenshot shows the Auckland District Health Board (ADHB) website. The header includes the ADHB logo with the tagline "Te Toka Tumai", a search bar, and social media icons for Facebook, LinkedIn, Twitter, and YouTube. A navigation menu lists "OUR SERVICES", "PATIENTS & VISITORS", "HEALTH PROFESSIONALS", "YOUR HEALTH", "ABOUT US", and "CONTACT US". The main content area features a large image of a modern hospital building. A pink call-to-action box on the right asks "Have a question?". Below the image, there is a breadcrumb trail: "Home > Contact us > Take part in our surveys & forums". The main heading for the section is "Take part in our surveys & forums". The text below reads: "We have a number of ongoing initiatives that allow you to get involved; to talk with us and other people in our wider community about how we can improve health outcomes and the services we deliver."

794 Next of Kin of people who had died after >1 contact with ADHB in their last 12 months of life completed the survey.

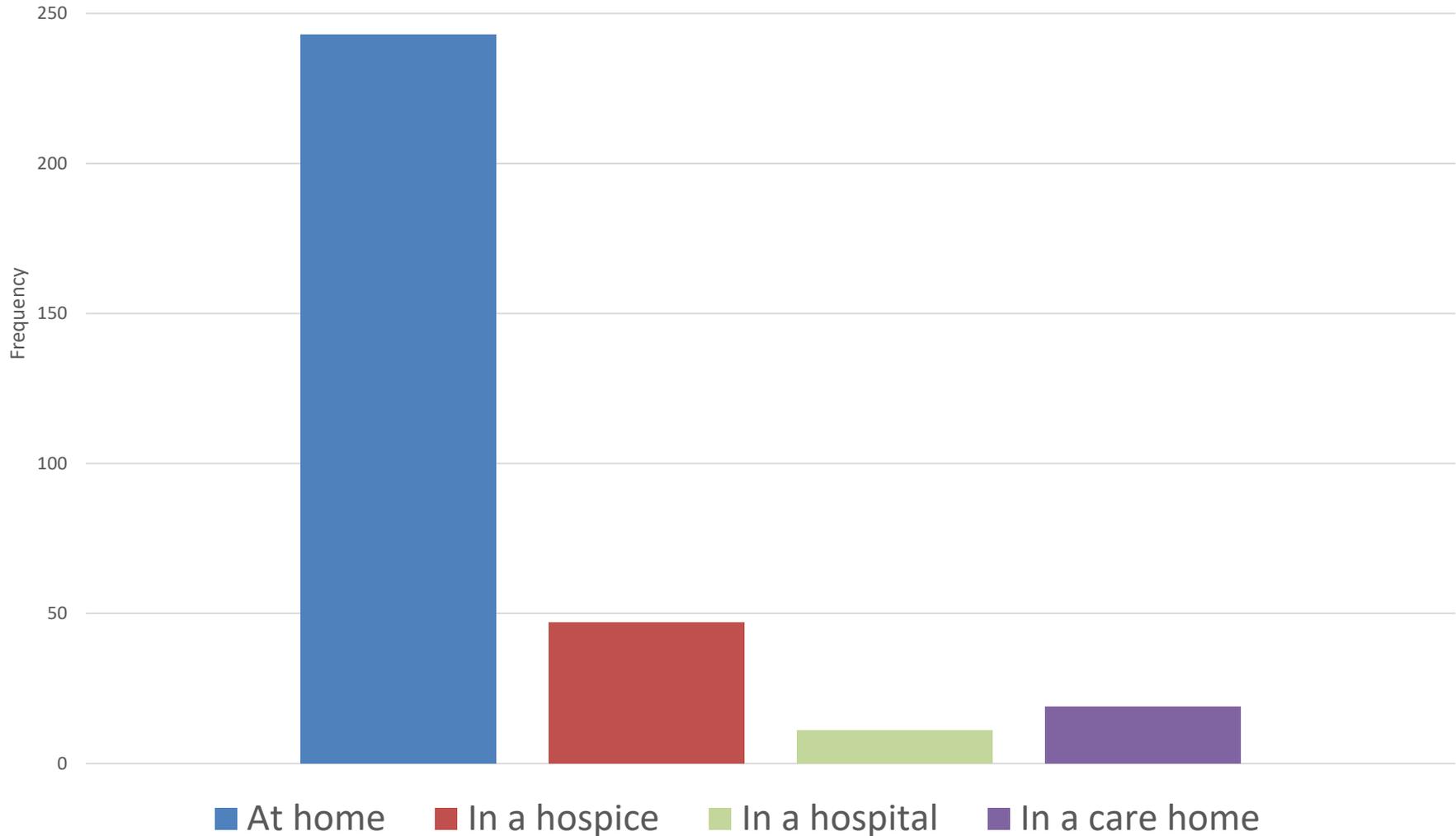
Satisfaction with care by setting



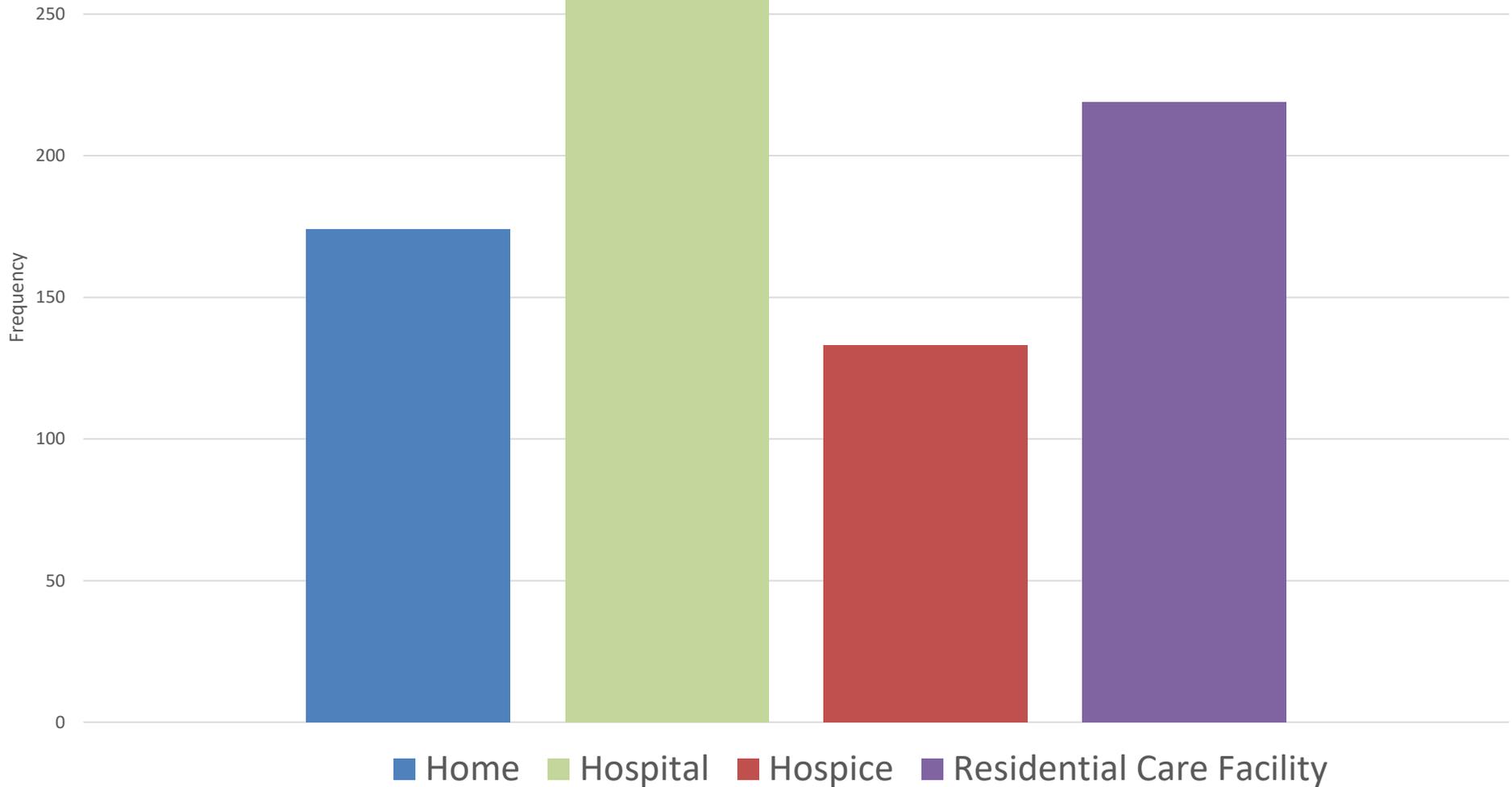
Sufficient pain relief by place of death



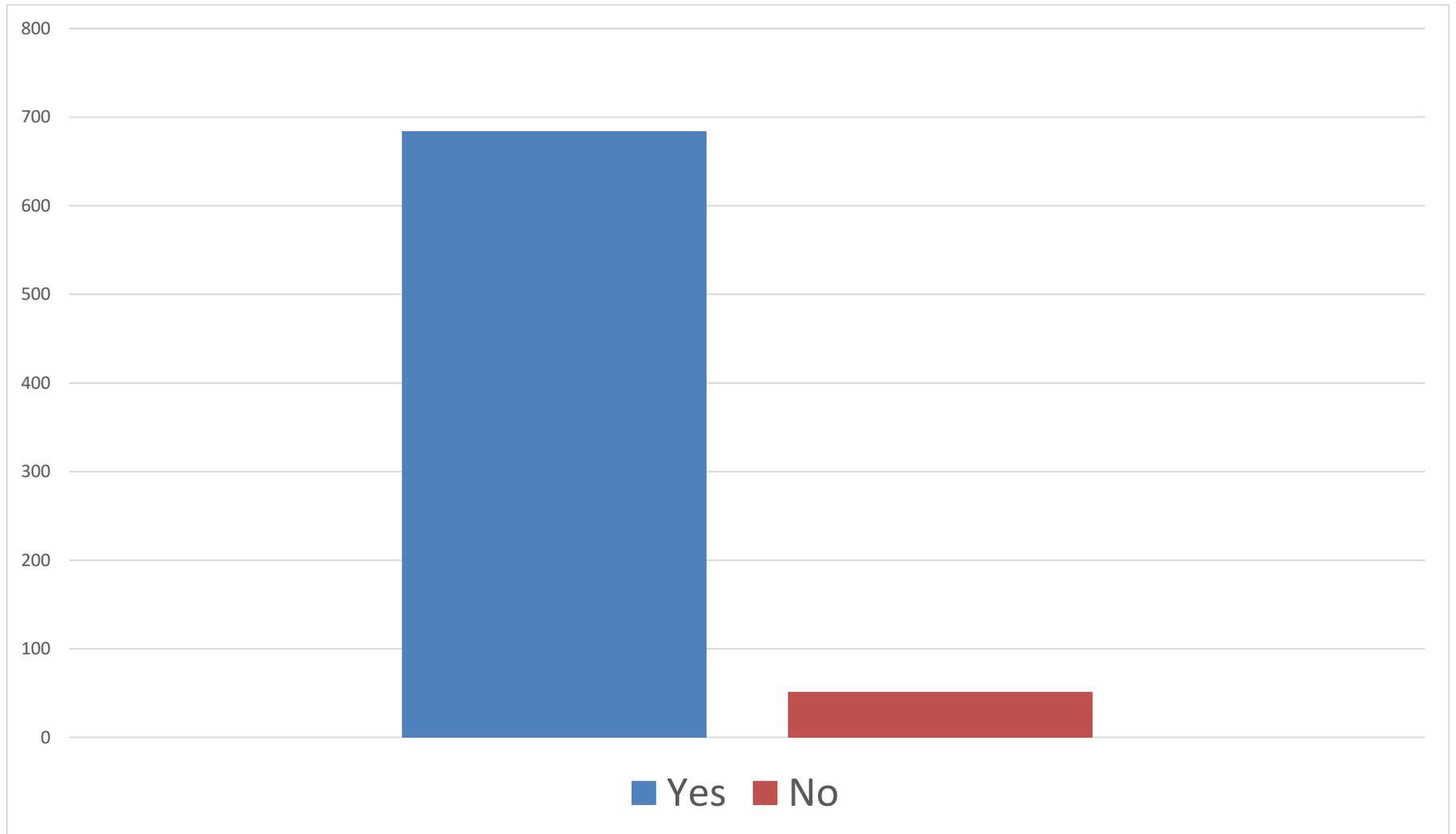
Preference for place of death



Place of death



Died in the 'right place'?



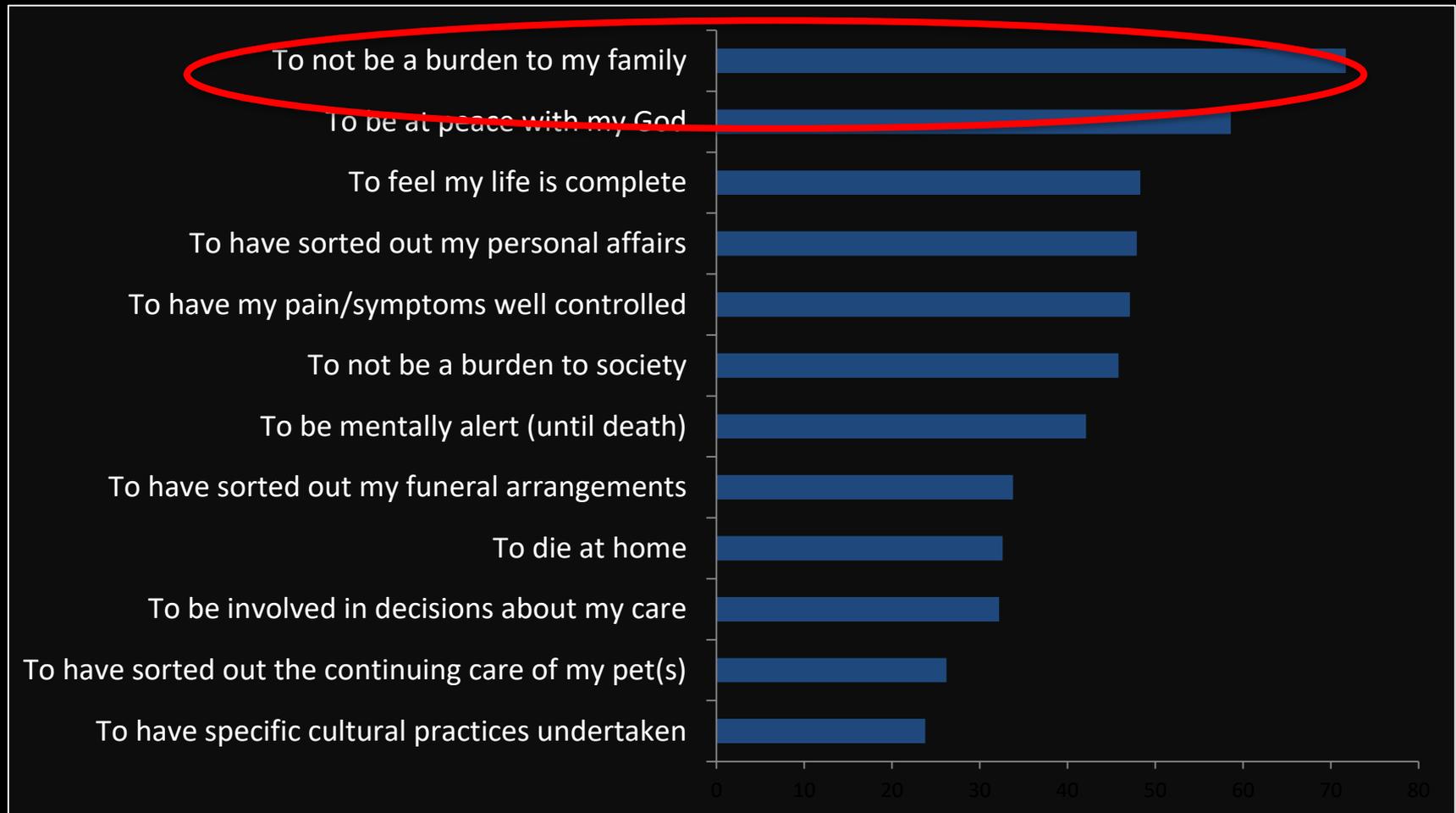
My home is not a nice place to
live...why do you think it would be a
nice place to die?

Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. Older people's views about home as a place of care at the end of life. *Palliative medicine*, 18(5), 460-467.

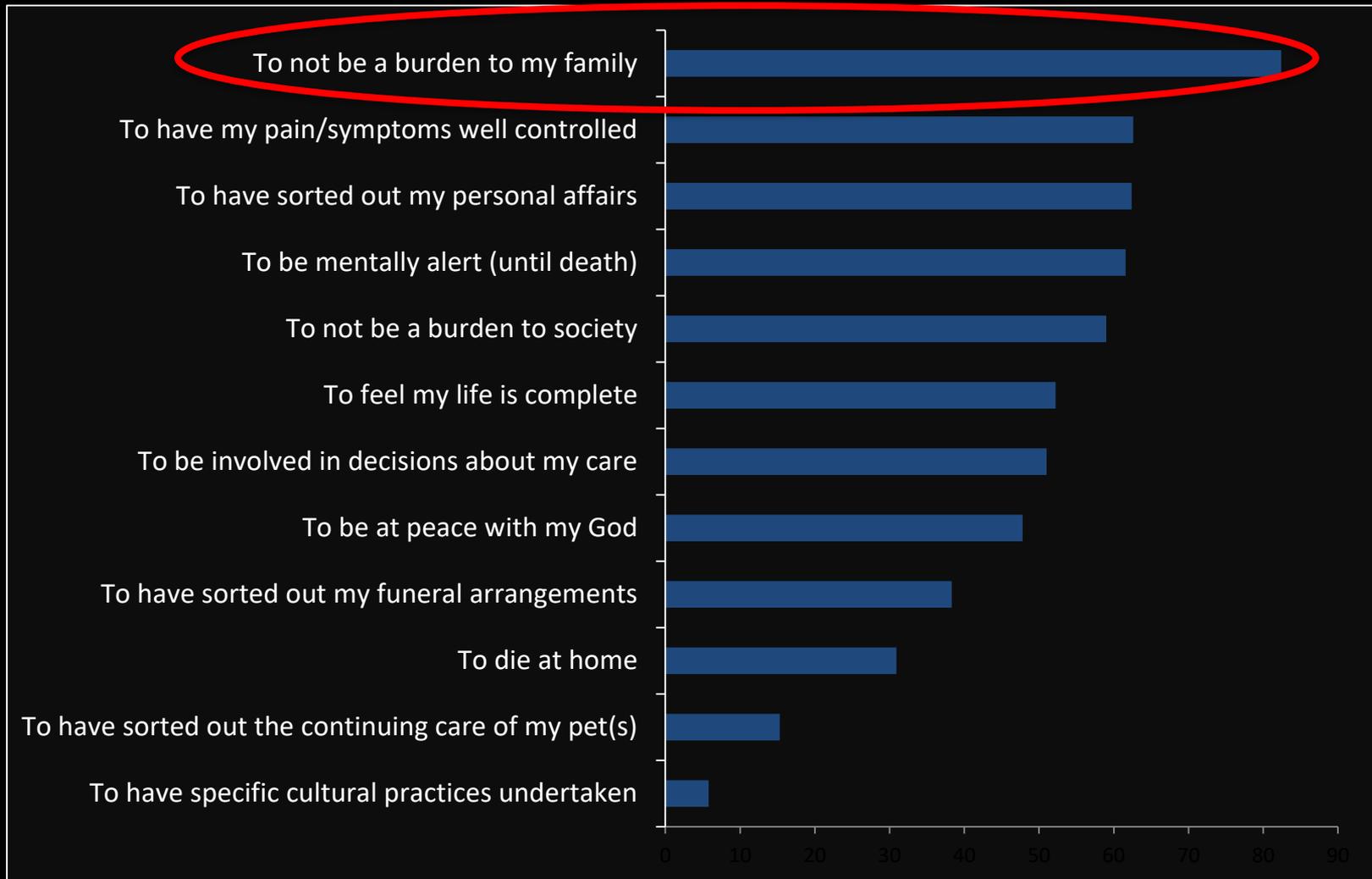


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What is “very important” to you at the end of life? (147 Māori aged over 80 years)



What is “very important” to you at the end of life? (291 non-Māori aged over 85 years)



Family and whānau are care navigators



Williams, L. A., Moeke-Maxwell, T., Wiles, J., Black, S., Trussardi, G., Kerse, N., & Gott, M. (2018). How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study. *Palliative Medicine*, 0269216318765853.

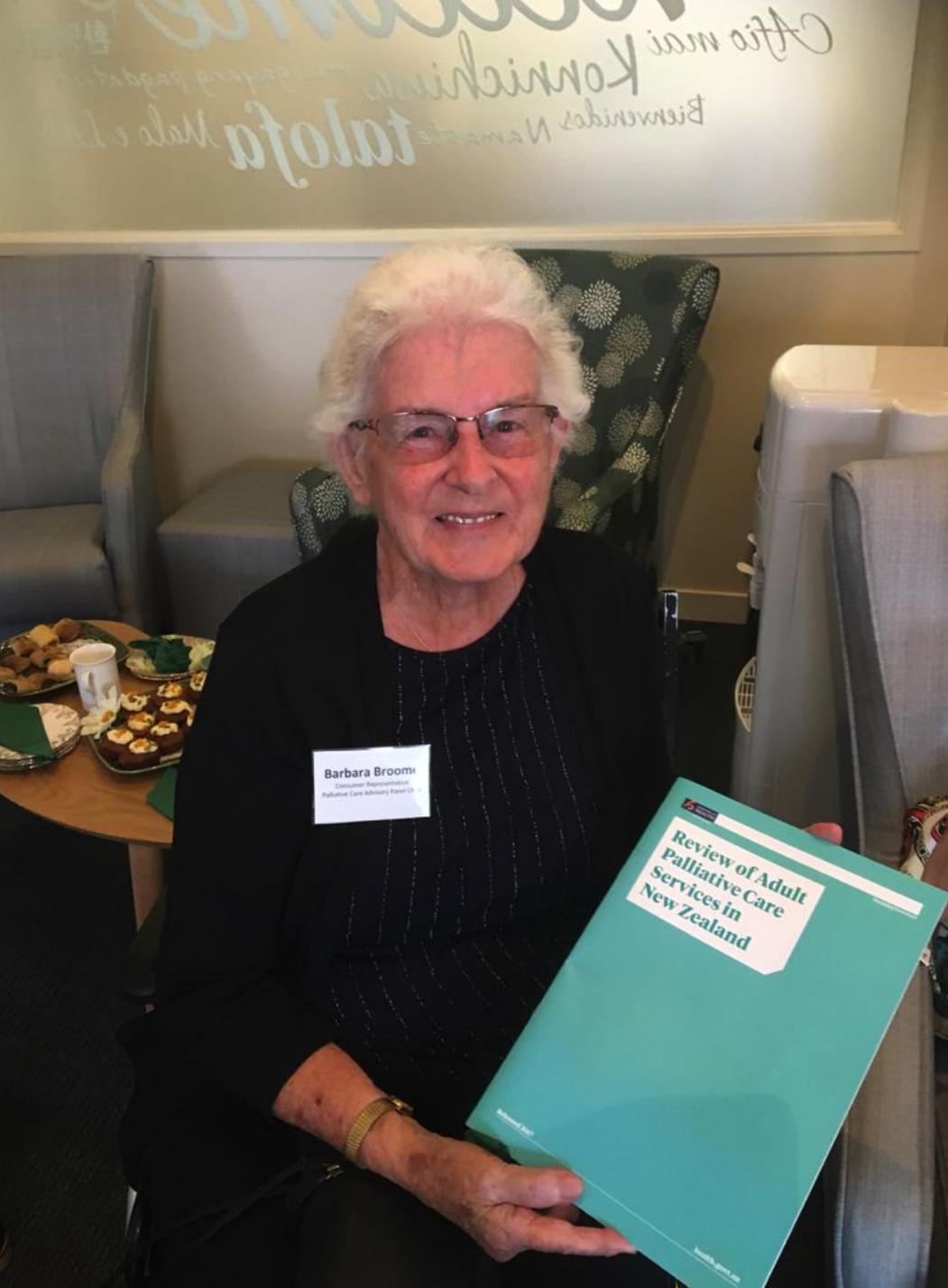
Dying is a feminist issue



Williams, L. A., Giddings, L. S., Bellamy, G., & Gott, M. (2017). 'Because it's the wife who has to look after the man': A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life. *Palliative medicine*, 31(3), 223-230.

Video





Five policy priorities:

1. Increase the emphasis on primary palliative care
2. Improve quality in all settings
3. Grow the capability of family carers and communities
4. Respond to the voices of people with palliative care needs and their families and whānau
5. Ensure strong strategic connections



'If only those with power ... would listen and incorporate the experience of those who have first hand knowledge of the reality of the situation on the ground – the results would transform the ideas of leadership and decision-making'.

Acknowledgments



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