

# Advocating for Equity:

## A case study of disability- inclusive cancer care

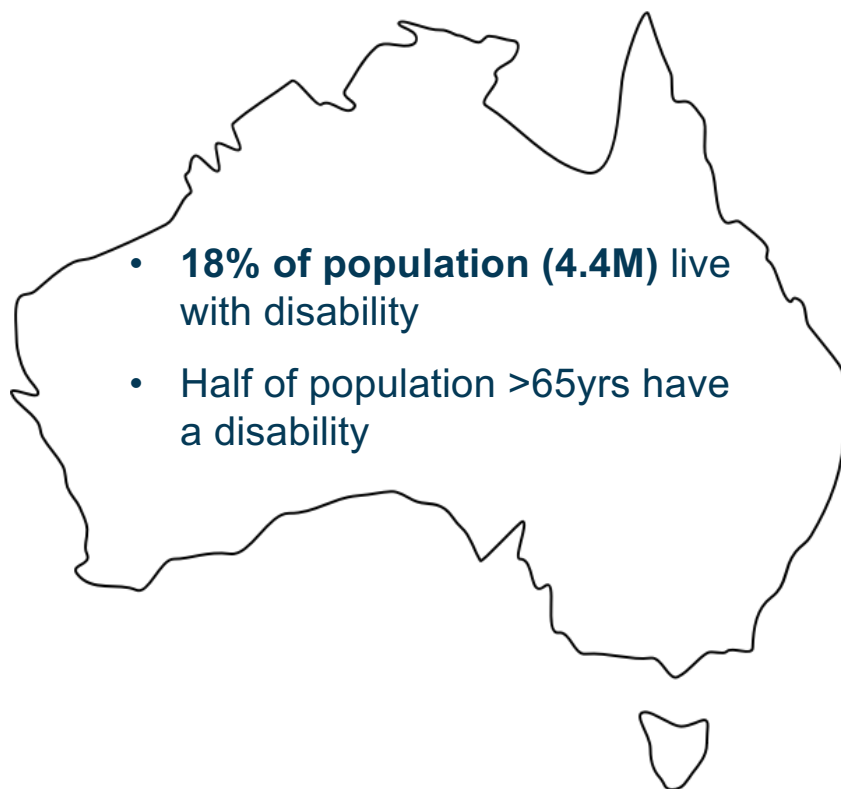


The Victorian Integrated Cancer Services are supported by the Victorian Government.



## Why equity in cancer care matters

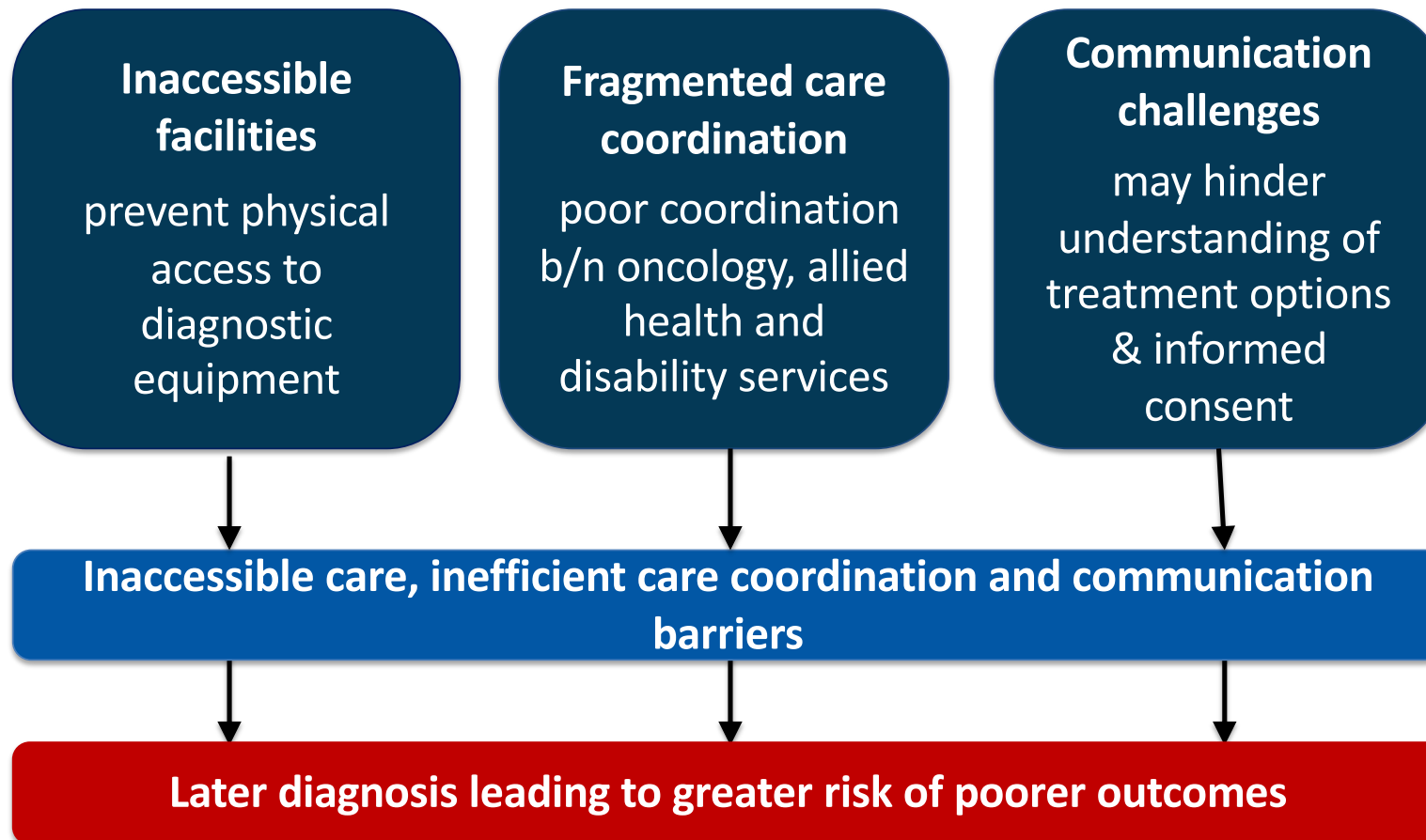
**People living with a disability have lower survival rates** than people without disability.



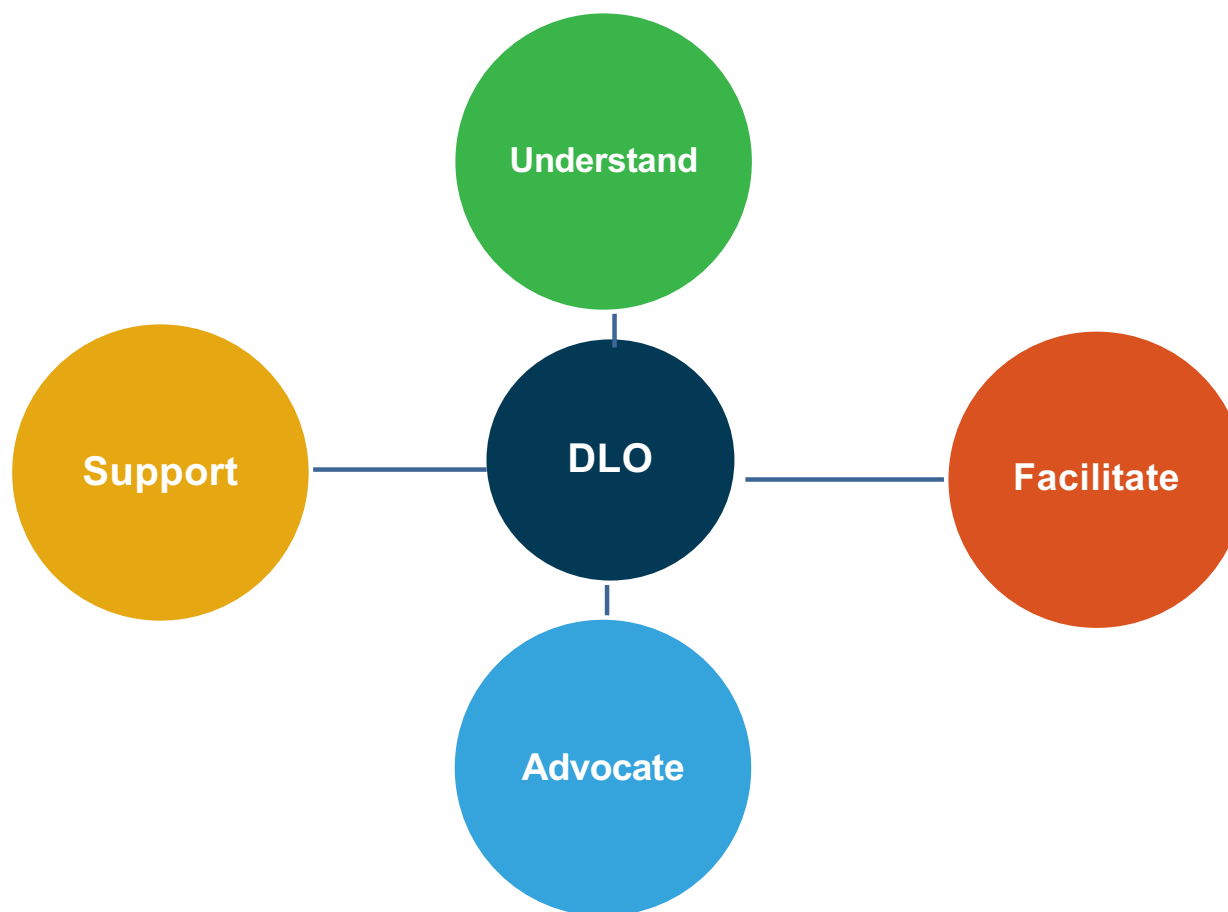
Australians living with disability **4 x more likely to die** early compared to people without disability (Women with disability **5 x more likely to die** early).

Cancer accounts for **~20% of the increased mortality rate** for Australians living with disability.

## Why are cancer outcomes worse if you live with disability?



## The role of the DLO



## Maria's Cancer Journey

Equity and compassion  
in disability-informed  
cancer care



## Maria & Christina

- Maria\* is a 63-year-old woman of East Timorese background.
- Diagnosed with **intellectual disability, schizophrenia, frailty.**
- Lives with elderly mother

### Cultural Norms

Eldest child assumes medical decision- making after the father's passing. This was Maria's sister, Christina\*.

### Challenges in Health Communication

Cultural taboos limit open discussion of disability and health.

### Caregiver Burden

Christina balances full-time work, family, and caregiving duties, under significant pressure managing Maria's health.

*\*Names have been changed to protect patient and family privacy and confidentiality.*



## Pre-diagnosis

- Trouble with bowel movements & weight loss
- Multiple ED presentations previous 2yrs - inconclusive diagnosis
- Re-presented to ED with severe abdominal pain
- Sister strongly advocated for CT scan
- CT findings consistent with **colorectal cancer**
- Surgeon discussed diagnosis, sister needed to advocate but limited understanding of clinical processes.

## DLO support

- Sister overwhelmed, connected with DLOs for support
- Provided emotional support and reassurance to sister, provided clear simplified information about Maria's condition and care
- Facilitated communication with treating teams
- Provided support in understanding risks, benefits and treatment options.
- Assisted sister in decision-making and next steps.



## Overcoming Access Barriers

- Clinicians doubted Maria could tolerate PET scan
- DLOs persisted, sought photos of the imaging machines to prepare Maria so she wouldn't panic during scan.
- Explored what helped Maria relax and feel safe - classical piano music, which DLOs played in ambulance on way to scan.
- DLOs created a story about the procedure including a cue to be '*still like a soldier*' as she moved through the machine.

### Environmental adjustments

- Dimmed lights, soft classical music playing when Maria arrived for scan
- Radiologist was informed of and repeated the cue to Maria to be '*still like a soldier*' prior to scan.



**Maria had a successful PET Scan**



## Support during surgery and recovery

### Informed surgical decision

- DLOs helped Maria's sister understand PET scan results, risks & benefits of surgery
- Maria's sister consented for Maria to undergo surgery

### Surgery

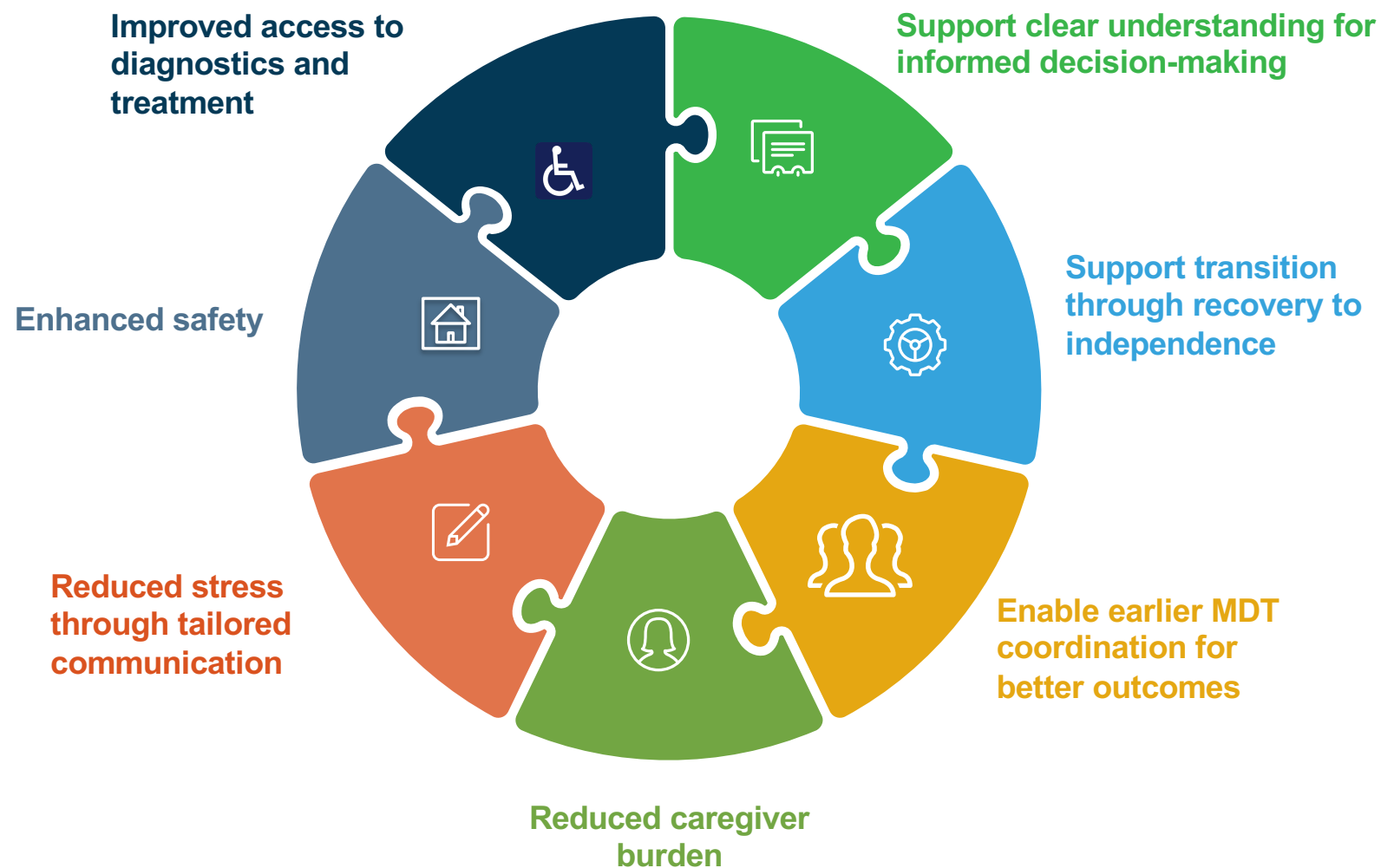
- DLO accompanied Maria to theatre, ensured she understood what to expect and stayed with her until she was asleep.
- Despite high risk and some complications, Maria's surgery was successful Maria was walking unaided within 3 weeks

### Recovery

- Maria is undergoing rehabilitation
- DLOs continue to advocate for Maria's ongoing care and independence



## Benefits of Cancer DLO



## Disability-informed Cancer Care Project

### Phase 1:

- Develop a toolkit to guide delivery of optimal cancer care for people with a disability.

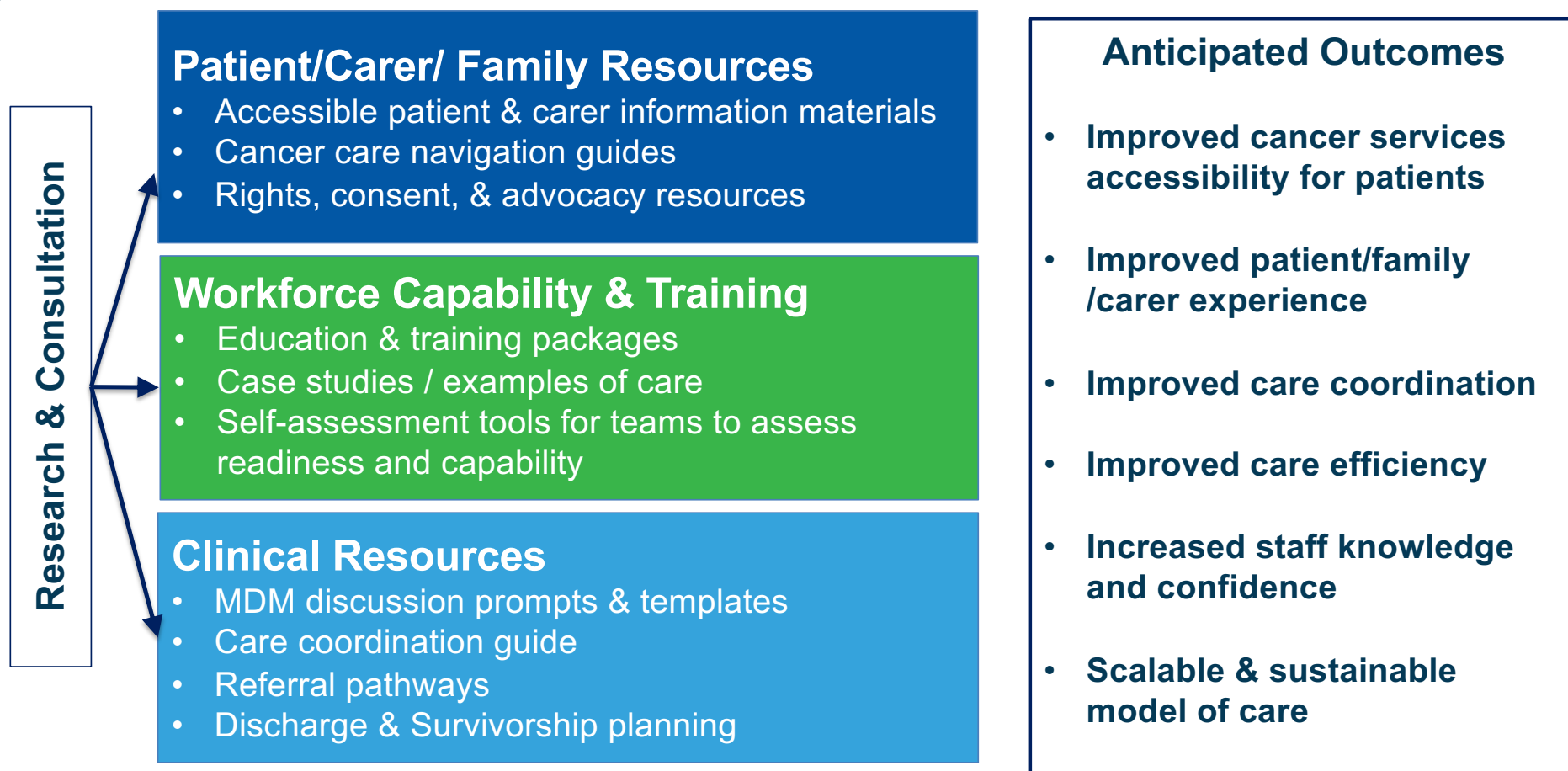
### Phase 2:

- Design and implement an integrated model of cancer care for people living with a disability

### Stakeholders

- SMICS member health services – Monash Health, Bayside Health (Alfred & Peninsula Care Groups), Cabrini
- SMICS
- Lived and living experience partners (LLEP)
- Peak bodies, community organisations

## Disability Cancer Care Toolkit overview



**Thank you**

