

*Inaugural Australian Implementation Conference  
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**Outside the silo:  
How do we conduct implementation  
research in 'hard to reach' and  
vulnerable populations?**

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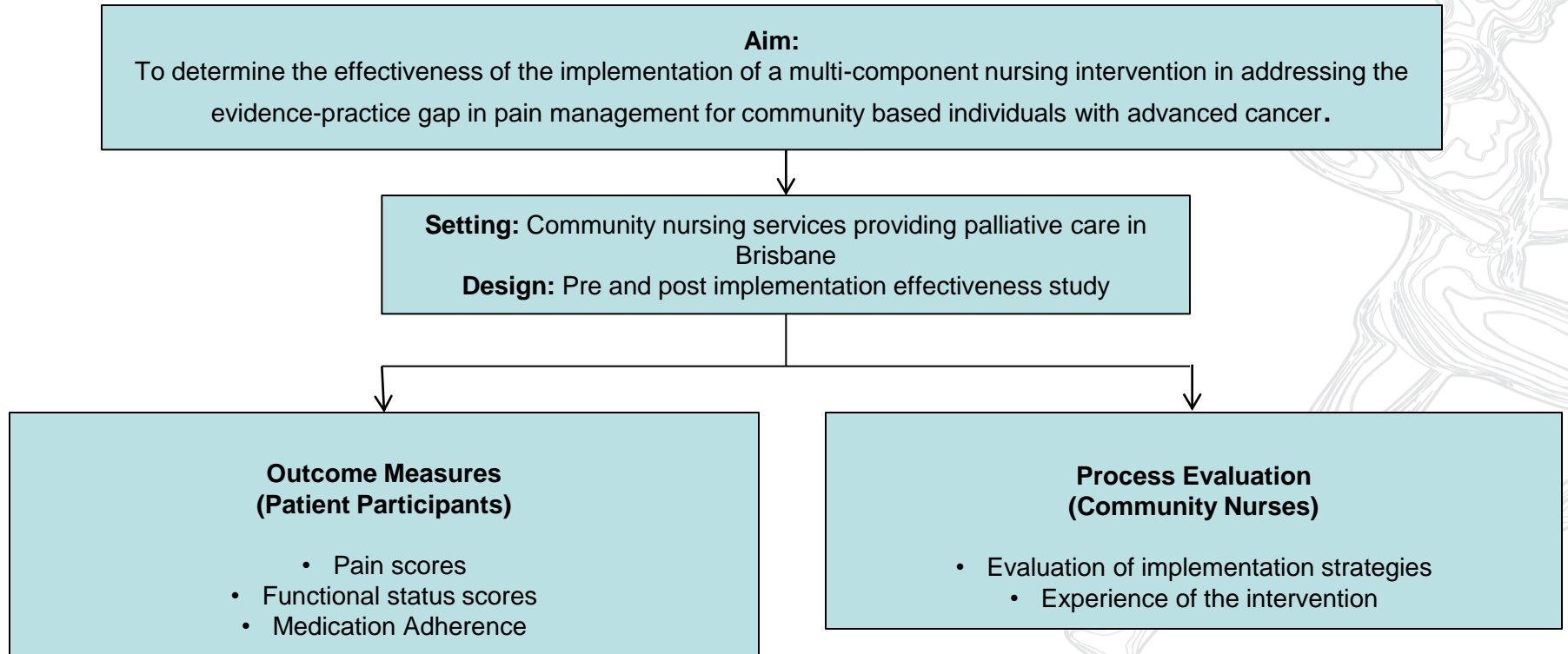


# Study 1:

Conducting implementation research  
in **people with advanced cancer, at  
the end of life** in the **community  
setting**



# Study 1:

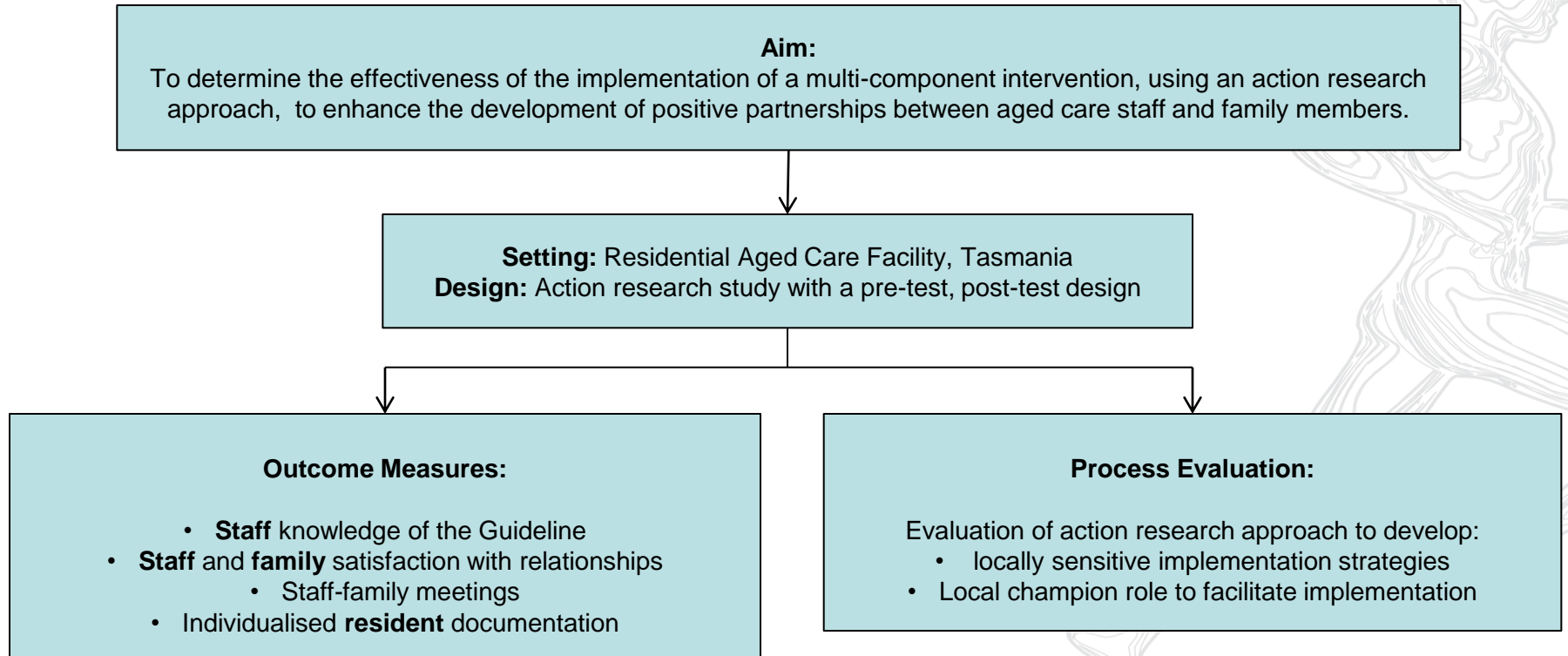


## Study 2:

Developing positive partnerships between aged care staff and family members of **people with dementia and other aged related conditions** in a **Residential Aged Care setting.**



# Study 2:



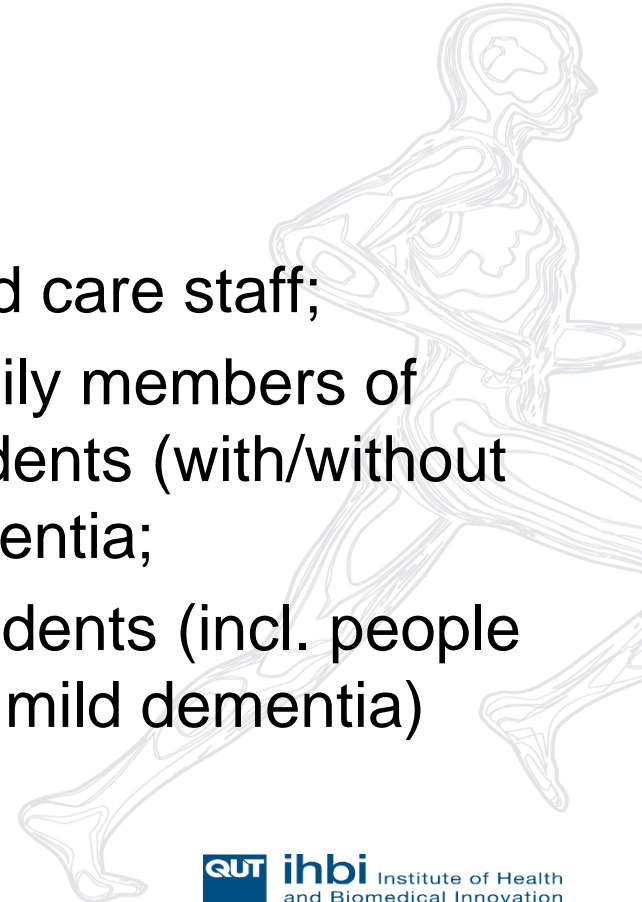
# Study Participants:

## Study 1

- Community nurses;
- People in the community, with a diagnosis of advanced cancer, in the last 6 months of life and experiencing pain

## Study 2

- Aged care staff;
- Family members of residents (with/without dementia);
- Residents (incl. people with mild dementia)



# Barriers

## **Systemic:**

Traditional taxonomies for levels of evidence

Funding

Human Research Ethics Committees

## **Health Professional:**

Gatekeeping

Lack of knowledge

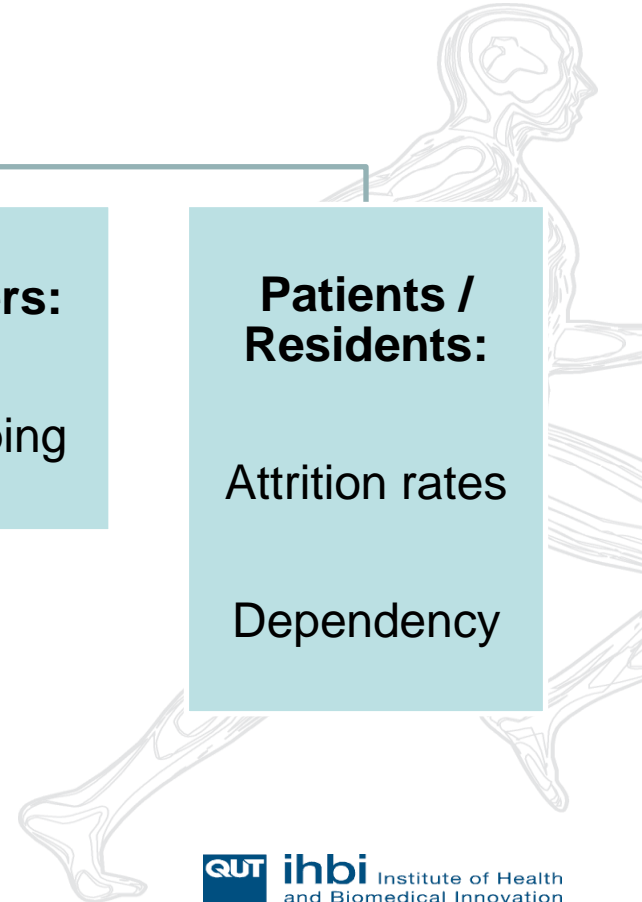
## **Caregivers:**

Gatekeeping

## **Patients / Residents:**

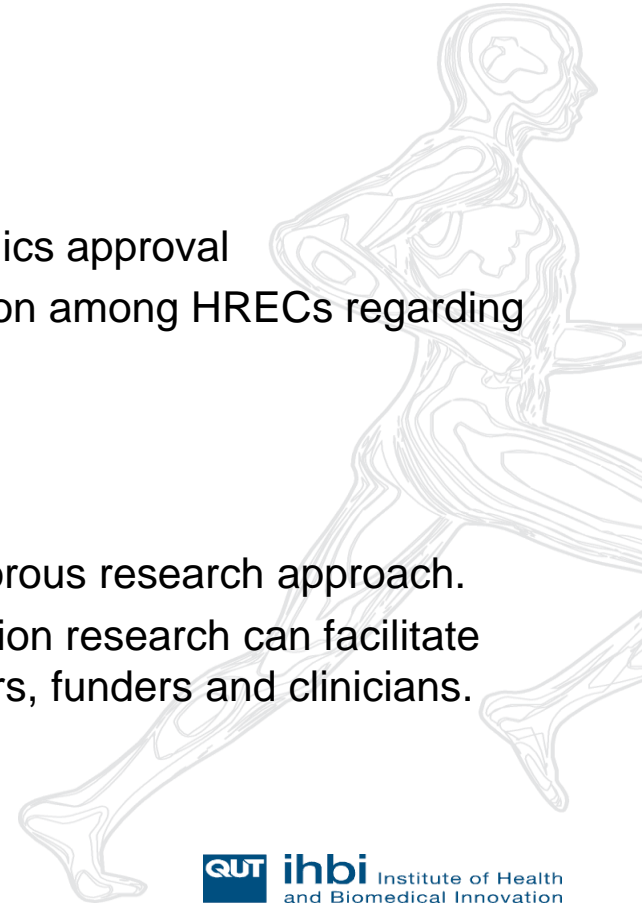
Attrition rates

Dependency



# Barriers - Systemic

- Study 1:
  - **Issue:** Challenging and lengthy processes to gain ethics approval
  - **Strategy:** Need for greater awareness and cooperation among HRECs regarding vulnerable populations
- Study 2:
  - **Issue:** Action research often not understood as a rigorous research approach.
  - **Strategy:** Need for greater awareness about how action research can facilitate the translation of evidence into practice by researchers, funders and clinicians.



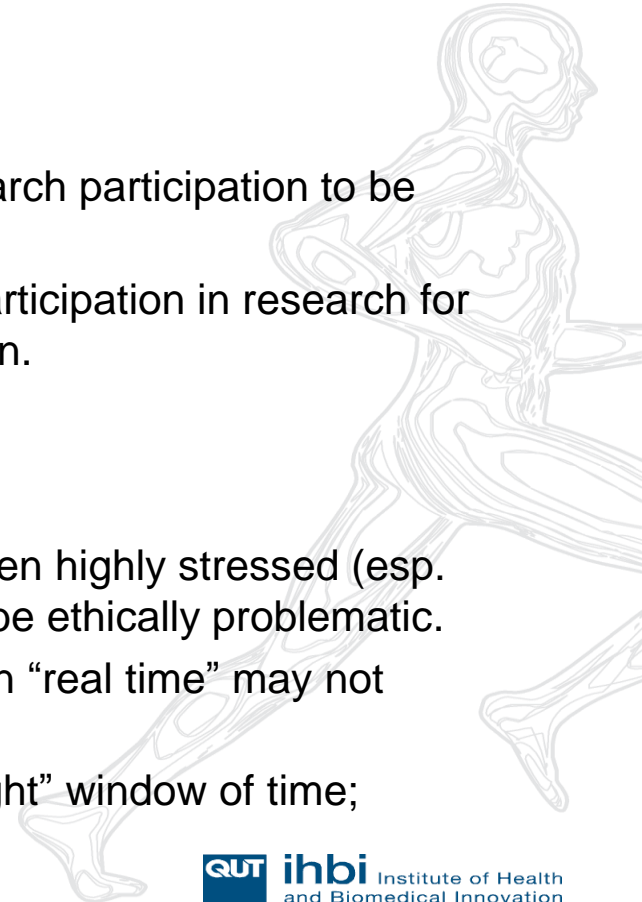


# Barrier: Health Professional

- Study 1:
  - **Issue:** Community nurses act as gatekeepers to potential participants, perceiving research as burdensome and stressful.
  - **Strategy:** Increasing awareness of health professionals about the benefits of participation in research for patients; and support.
- Study 2:
  - **Issue:** Residential aged care staff often function in isolation from other areas of health care sector, having limited engagement with implementation research or practice development.
  - **Strategy:** Capacity building activities so that clinicians can champion evidence based change; strategies that promote networking across the sector .

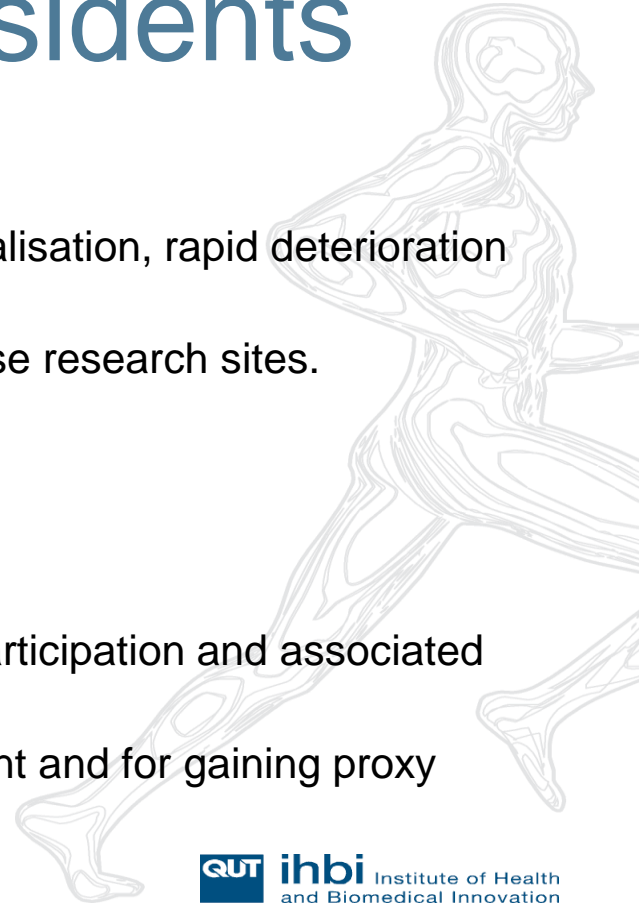
# Barriers: Caregivers

- Study 1:
  - **Issue:** Family members of patients often perceive research participation to be burdensome and stressful.
  - **Strategy:** Educating caregivers about the benefits of participation in research for patients. Providing additional support during participation.
- Study 2:
  - **Issue:** Family members of people with dementia are often highly stressed (esp. around time of admission to a facility)- recruitment can be ethically problematic.
  - Implementation to test effectiveness of an intervention in “real time” may not always be appropriate.
  - **Strategy:** Gain permission to follow-up - finding the “right” window of time; Retrospective feedback and piloting of intervention.



# Barriers: Patients / Residents

- Study 1:
  - **Issue:** High attrition rate of participants due to hospitalisation, rapid deterioration and death
  - **Strategy:** Lengthy data collection periods and increase research sites.
  
- Study 2:
  - **Issue:** Problems with gaining informed consent for participation and associated ethical implications.
  - **Strategy:** Processes for assessing capacity to consent and for gaining proxy consent;



Thank you for listening.

