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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:

#### Aim:

To determine the effectiveness of the implementation of a multi-component nursing intervention in addressing the evidence-practice gap in pain management for community based individuals with advanced cancer.

**Setting:** Community nursing services providing palliative care in Brisbane

**Design:** Pre and post implementation effectiveness study

## Outcome Measures (Patient Participants)

- Pain scores
- Functional status scores
- Medication Adherence

### Process Evaluation (Community Nurses)

- Evaluation of implementation strategies
  - Experience of the intervention



## 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:

#### Aim:

To determine the effectiveness of the implementation of a multi-component intervention, using an action research approach, to enhance the development of positive partnerships between aged care staff and family members.

**Setting:** Residential Aged Care Facility, Tasmania **Design:** Action research study with a pre-test, post-test design

#### **Outcome Measures:**

- Staff knowledge of the Guideline
- Staff and family satisfaction with relationships
  - Staff-family meetings
  - Individualised resident documentation

#### **Process Evaluation:**

Evaluation of action research approach to develop:

- locally sensitive implementation strategies
- Local champion role to facilitate implementation



## 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;



