

The ladder of research utilisation: Implementing consumer-led research

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Health Care Consumers' Association (HCCA)

HCCA encourages and supports consumers to be involved in all levels of health service planning and decision making.

As a consumer advocacy organisation, we want our research to drive quality improvement and policy change.

The research

HCCA undertook research into consumer and carer expectations and experiences of home-based palliative care. We used several strategies to scale the research utilisation ladder, building on a strong foundation of consumer involvement in research.

The research utilisation ladderⁱ

Researchers will have more influence on knowledge users if they

- tailor their research findings to the needs of the knowledge users, and
- intensify their interactions with knowledge users.

Any activities undertaken to engage potential users in one's research are known as *knowledge mobilisation strategies*.ⁱⁱ

Outcomes

Our consumer-led research into consumer experiences and expectations of home-based palliative care has underpinned much of the work we have undertaken.

Our repeated engagement with potential knowledge users

- built durable relationships with clinicians, policy-makers and health service managers,
- resulted in changes to a model of care, and
- contributed to the appointment of a paediatric palliative care nurse.

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ACT Health Human Research Ethics Approval 3.17.051

Calvary Public Hospital Human Research Ethics Approval 23.2017

ⁱ Knott, Jack and Aaron Wildavsky. 1980. 'If Dissemination is the Solution, What is the problem?' *Knowledge: Creation, Diffusion, Utilisation*, Volume 1, Number 4, June 1980, pages 537-578.

ⁱⁱ Cooper, Amanda. 2014. 'Knowledge mobilisation in education across Canada: A cross-case analysis of 44 research brokering organisations. *Evidence and Policy*, 10, pages 29-59.

Implementation and impact

The plans and policies translate into practice or has the desired effect

Only time will tell....

Adoption

The research influences plans and policies

- HCCA comments have been incorporated:
 - Model of Care – Acute Integrated Palliative Care Unit,
 - Paediatric Palliative Care Nurse position.
- Awaiting outcome of the ACT Legislative Assembly Select Committee Inquiry into End of Life Choices in the ACT

Reference

The research changes the way policy-makers see the world

PCCN indicated that the HCCA findings were broadly consistent with professionals' understanding and experience. They also refer to the report in conversation

Cognition

The knowledge users read, digest and understand the research

- ACT Palliative Care Clinical Network (PCCN) asked questions, gave feedback, and prioritised recommendations
- Health department acknowledged HCCA feedback on
 - Model of Care–Acute Integrated Palliative Care Unit
 - Paediatric Palliative Care Nurse position
- ACT Legislative Assembly Select Committee Inquiry into End of Life Choices in the ACT considered research-based submission.

Transmission

The research comes to rest in the 'in-basket' of knowledge users

Results presented in different ways to

- Governments
- Clinicians, policy-makers and health services managers
- Community members and clinicians:
 - CareSearch guest blog
 - HCCA Consumer Representatives Forum.

Collaborative consumer involvement

- Consumer initiated
- Consumer oversight
- Consumer participants
- Consumer prioritised recommendations
- Real People Real Data method
- Consumer Advisory Group