

Research Article



Establishing a research partnership to investigate functional loss and rehabilitation towards the end of life

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Plain language summary

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'Functional loss' describes a person becoming unable to do the everyday activities they would like or need to do. Lifelimiting illnesses and their symptoms can often lead to functional loss: a common source of suffering for patients and their families.

Rehabilitation aims to support a person to carry out everyday activities that have been affected by illness. This should be an important part of providing good palliative care. However, in practice, not everyone has equal access to rehabilitation and there is a lack of high-quality research in this area.

The Palliative Care Rehabilitation Partnership was created to begin to address these challenges. This partnership completed activities in five key areas:

- 1. Establishing the partnership Brought together experts from different fields, like palliative care, care for older people and research, to improve rehabilitation for people with life-limiting illnesses.
- 2. Generating research questions Collected and ranked research questions about functional loss and rehabilitation from various stakeholders, including patients, to identify key research areas.
- 3. Developing research proposals Helped, through workshops, turn these research questions into detailed proposals for funding. This involved refining ideas, discussing how best to conduct the studies and getting feedback.
- 4. Building capacity and capability Provided training opportunities for its members, including clinicians, researchers and patients, to improve their research and rehabilitation skills. It also offered mentorship to people with dual roles as clinicians and researchers.
- 5. Service mapping Improved our understanding of services for functional loss and rehabilitation across different healthcare settings.

The Palliative Care Rehabilitation Partnership has made gains in addressing the complex issues of functional loss and rehabilitation in people with life-limiting illnesses. The partnership has supported the development of at least three new research proposals that will be used to apply for future funding.