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‘Who is this person and what do they need from me today?’

Enhancing clinical care for people with long-term neurological conditions



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Background

Long-term neurological conditions result in significant personal, whānau/family and societal burdens that can be reduced with good quality care and support. However, consumers’ expectations of quality care, including person-centred communication and continuity of care, are often not translated into routine practice. Evidence suggests that active strategies (e.g. co-design, knowledge brokerage) are required to support such translation.



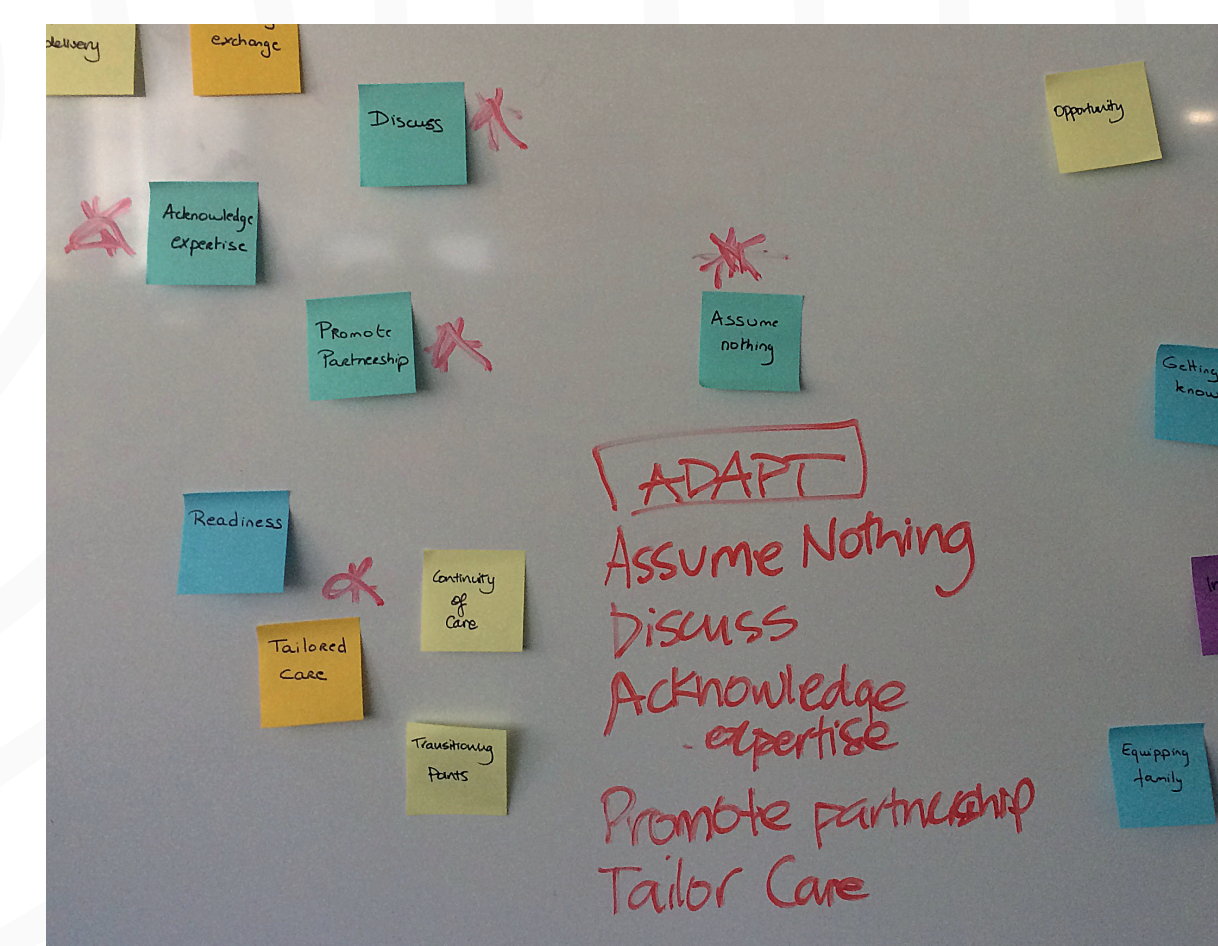
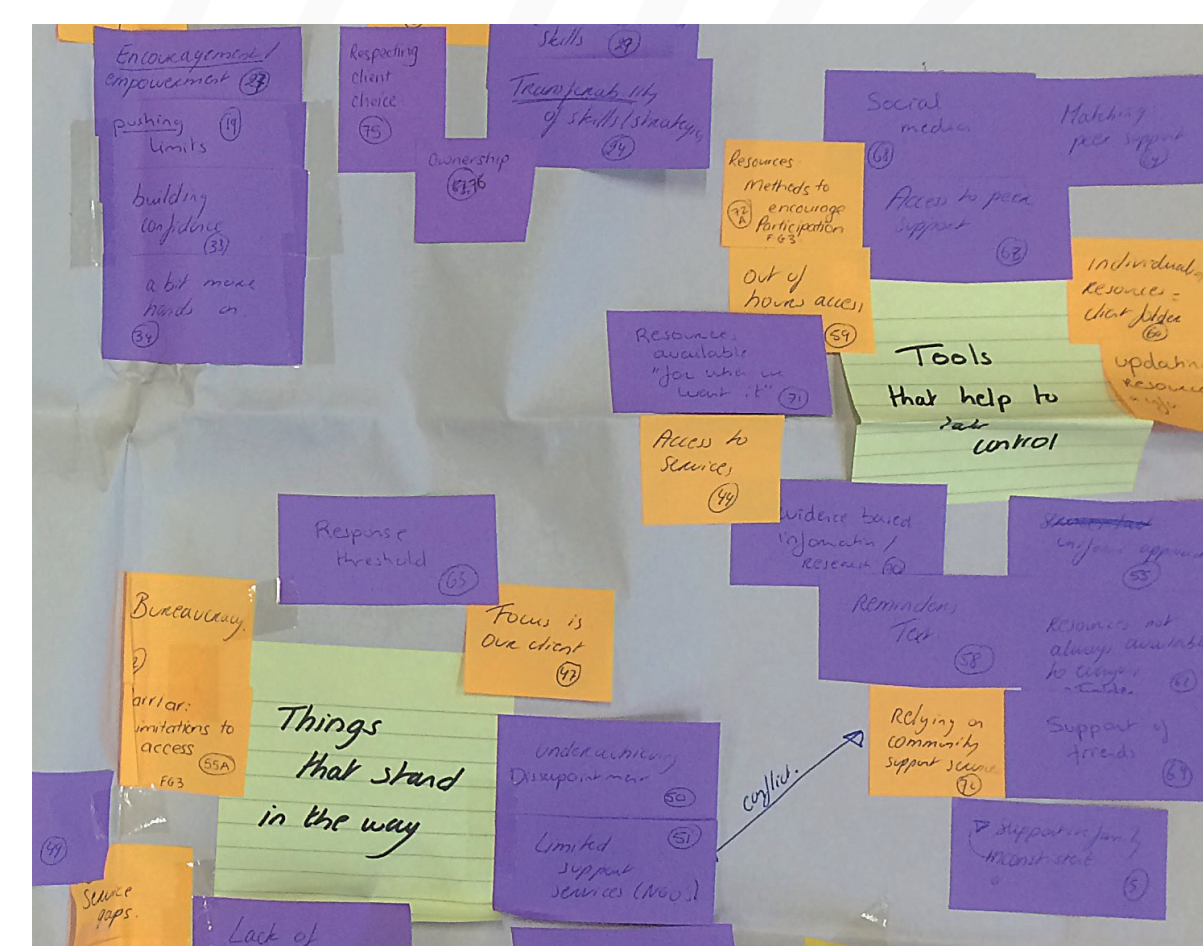
Objectives

We aimed to design and implement a toolkit with consumer guidance, targeting specific processes in the long-term care pathway to act as structural support to:

- 1 improve communication
- 2 build strengths and harness skills to live well
- 3 enhance continuity of care

Method

Drawing on the philosophy of client-centred care, we used focus groups and interviews to explore how to best operationalise support for these processes. Discussions were audio-recorded, transcribed and data coded into meaningful segments. Conventional content analysis was used to identify categories common to all three processes and subsequently guide the development of toolkit prototypes. Input on the prototypes was invited from two additional groups: a knowledge users group (service users, family members, representatives from advisory and service organisations) and an implementation committee (clinicians from key localities).



Results

Participants comprised people living with neurological conditions, family/whānau and clinicians contributed to focus groups (n=11) and interviews (n=14). Five themes were common to the three processes: **Assume nothing**, **Discuss**, **Acknowledge expertise**, **Promote partnering** and **Tailor care** (ADAPT). In collaboration with designers from the Design for Health and Wellbeing Lab (DHWLab), these five themes were operationalised in a paper-based toolkit and a clinicians’ resource. The paper-based toolkit comprises three sections: ‘all about me’, ‘my needs today’ and ‘significant people in my life’. The toolkit is intended to be kept by the patient and used as they wish in health interactions. Key principles of knowledge translation were applied in the production of the toolkit. The clinicians’ resource is a layered and interactive electronic file, which provides more detail of and data underpinning ADAPT. In addition, following input from the implementation committee, a printed bookmark featuring the central orienting question ‘Who is this person and what do they need from me today?’ was produced.

Conclusions

In practice, the toolkit addresses key steps to both empower people with neurological conditions, and support structural or system changes. Facilitating enhanced interaction between provider and client/s is key to enhancing outcomes. These findings emphasise the value of understanding (and contextualising care by recognising) each patient as a unique individual, and taking time to listen to what is meaningful and important to them should not be underestimated. The Living Well Toolkit and accompanying clinicians’ resource attempt to apply the key themes of this research into a workable solution that has the potential to be implemented widely. Future phases of this project will pilot and refine the toolkit before rolling out in a wider implementation trial.

