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POSTER ABSTRACT

Understanding and optimising MND care coordinator roles in Australia

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Zoi Triandafilidis[1,2], Karen Hutchinson[1,2,6], Julie Labra[3], Nicholas Goodwin[2,4], Lois Quick[5], Yvonne Zurynski[6], Georgia Fisher[6], Barry Werth[7,8], Janet Hough[7], Anne Hogden[1]

1: UNSW, Australia
2: Central Coast Local Health District, Australia
6: Macquarie University, Australia
3: MND Australia
4: National University of Singapore
5: Metro South Health, Australia
7: National MNDA Lived Experience Network, Australia
8: The Unive

Background: Care coordinators play an important role in helping people living with motor neurone disease (MND) to navigate complex health and social care systems. However, their scope of practice, integration, and impact remain poorly understood and inconsistently applied across Australia. This project aims to co-design a MND care-coordinator model, tailor-made for the Australian context.

Approach: This mixed-methods study maps the current practices of MND care coordinators in Australia and identifies barriers and facilitators to their effectiveness. In Stage one, we will conduct online surveys and interviews across Australia with people living with MND and their family carers (referred together as PLEx), MND care coordinators, and health and social care professionals who work with MND care coordinators.

A descriptive analysis of survey data will be conducted simultaneously with a hybrid thematic analysis, inductive and deductive, informed by the Consolidated Framework for Implementation Science, COM-B and classifications of care coordinator roles in the research literature. These findings will inform Stage two, a co-design process, led by a Stakeholder Advisory Group including PLEx, MND Care coordinators, researchers, and health and service providers from across Australia to develop a tailored framework to optimise the role of MND care coordinators.

Results: We will present the preliminary findings from Stage one: the online survey and interview data, which will be collected and analysed in the first quarter of 2026. These findings will provide greater knowledge and understanding of current practices, responsibilities, integration, organisational structure and the barriers and facilitators impacting the MND care coordinator role.

Implications: We hypothesise that the findings from this research will ensure we: a) create a more efficient, connected, coordinated and sustainable model of MND care coordination for PLEx; b) improve equity and access to quality care that optimise outcomes no matter where people live; c) provide a flexible framework and set of competencies for MND care coordinators to support diverse needs and circumstances of PLEx; d) leverage existing resources to integrated MND care coordinators' roles into routine practice; and e) provide the vital link to improve translation of research into clinical practice. Findings are relevant to the development of care coordination models for MND and other rare and complex life-limiting conditions internationally. The study will also inform the Australian MND national guidelines, which are currently under development.