

Health Care Research in Australia

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Health
Central Coast
Local Health District

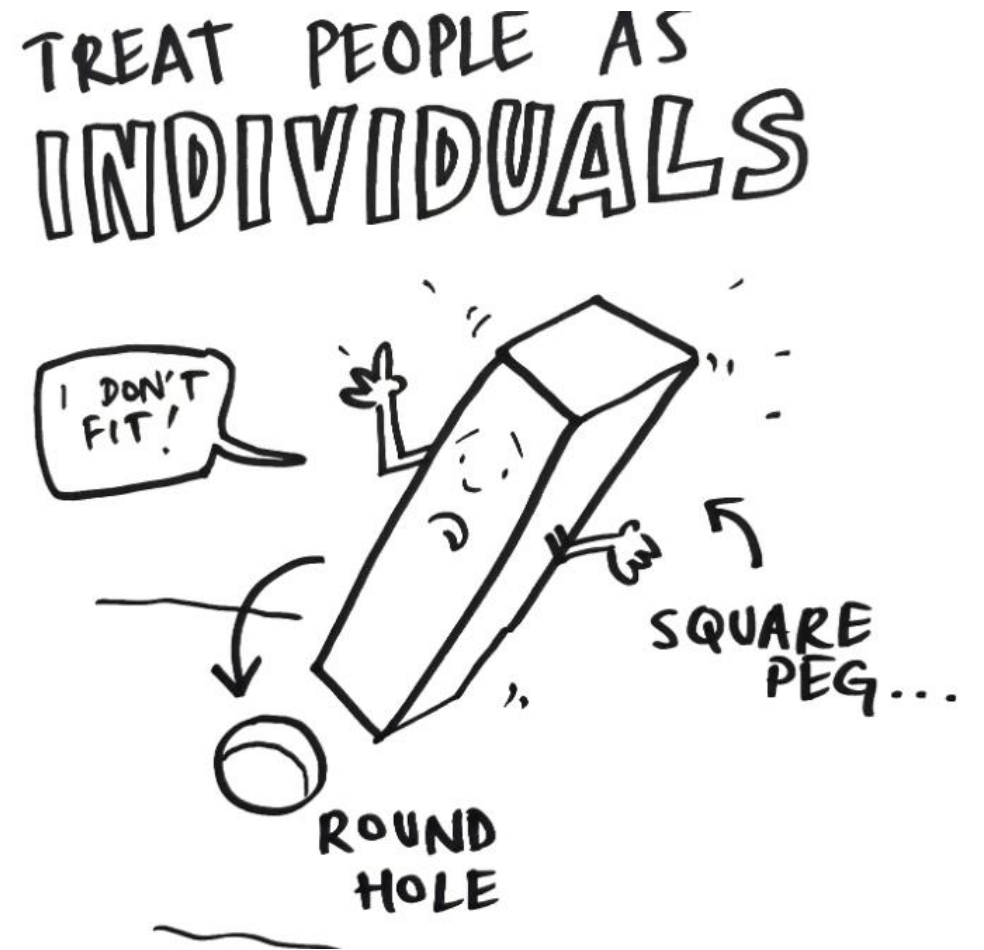
CCRI
Central Coast
Research Institute
for Integrated Care



**“Until there is
a cure, there
is care”**

Aoun et al 2018

*People and family centred care
according to specific needs and
priorities*



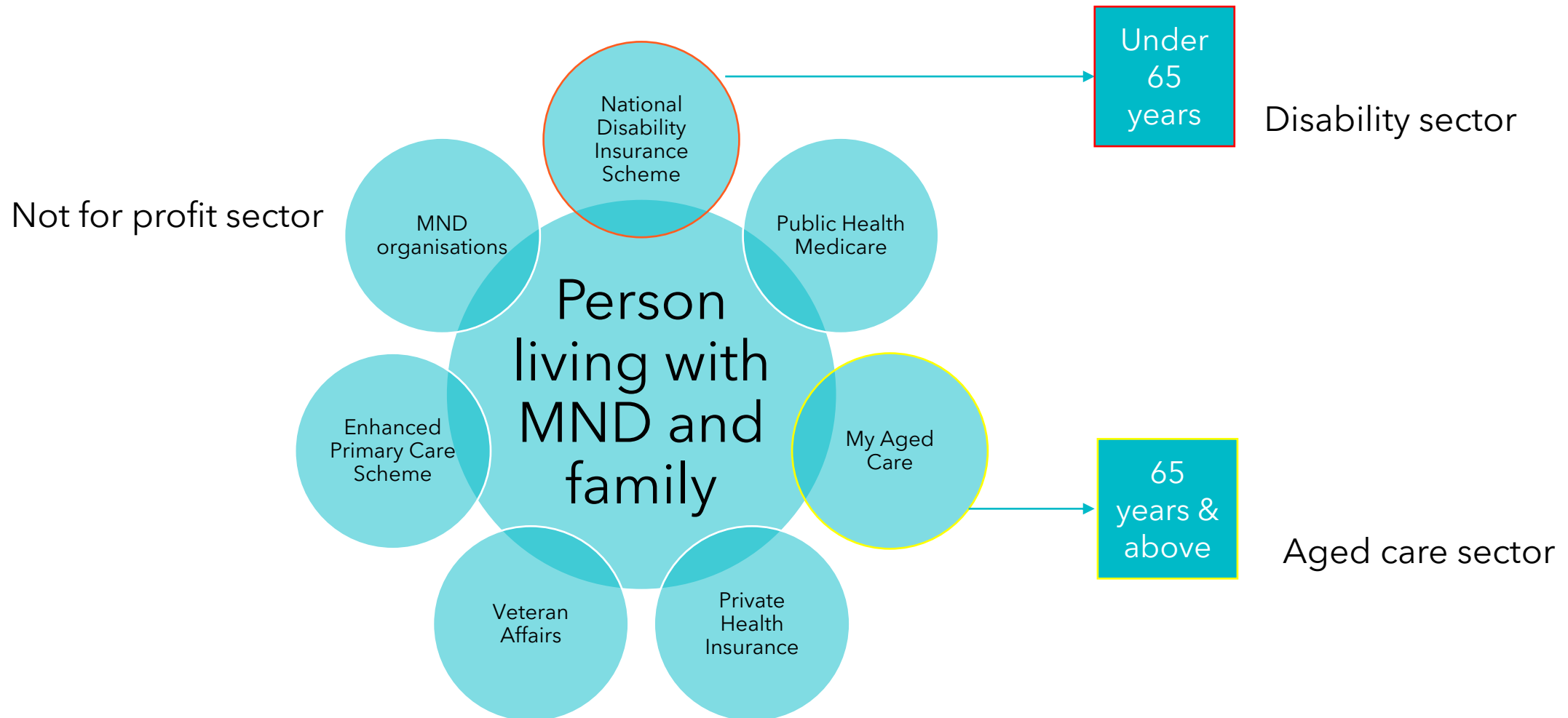
Delving deeper to gain understanding to know what needs to change?

First impression of this picture we acknowledge the detail and complexity but it's not until we look at it really closely do we see so much more.

Can you find the owl?



Health and Social Care Funding



Background – what do we know?

Quality Services

Person-centred care (PCC), integrated care and access to specialised motor neurone disease (MND) multidisciplinary clinics (MDC) are optimal approaches to the delivery of **quality services** for people living with MND (plwMND) for improved **quality of life** and **care experiences**.

Current Australian Funding Models

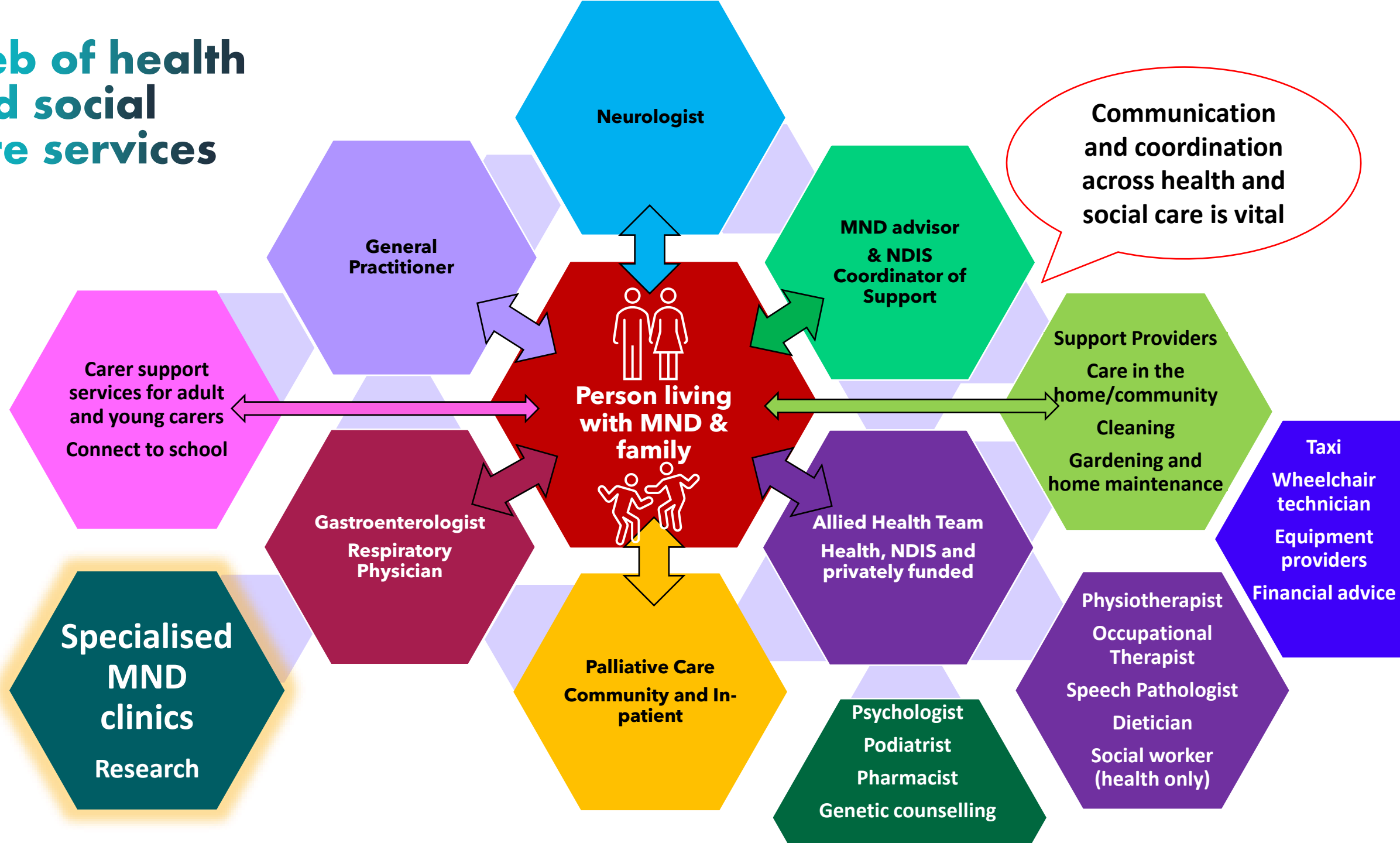
Current funding models of Australian care and support from diagnosis to end of life care, have **created barriers to equitable, timely, efficient, and connected care** for all plwMND.

NDIS development described as "a plane being built during flight" Malbon et al (2017)

Locality of specialised services

Most specialised MND clinics are currently **city based**, which can be a **barrier** to people attending from **regional, rural and remote areas**.

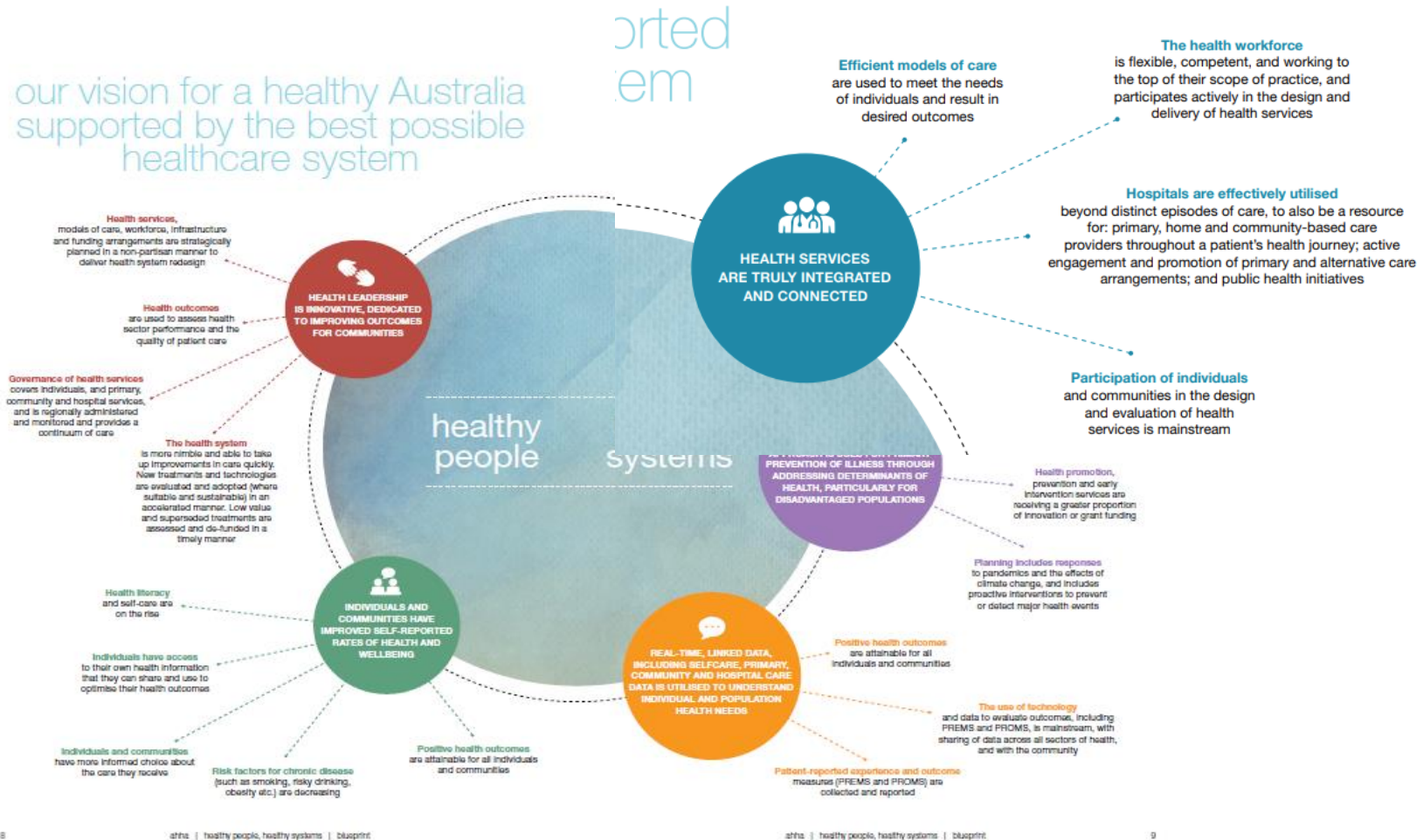
Web of health and social care services



What is integrated care

- 1. Integrated care** overcomes fragmentation of care delivery to coordinate care centred on individual needs to improve care experiences and outcomes
- 2. Integrated care** is an approach to improve quality of care and cost effectiveness of care, coordinated around individual needs.
 - a) People-centred
 - b) Population-orientated
- 3. Integrated care** takes a person-centred focus to service innovations, related to individual, family/ caregivers and wider community they belong

Vision for healthy Australians



Quadruple Aim



Snapshot of healthcare research



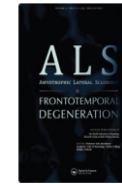
MiNDAUS

The goal:
improve care and coordination and to develop a national framework accumulating real-time, quality-controlled data to inform best practice service provision, research, standardization, and implementation of more effective clinical trial designs to facilitate the development of a cure and provide a more adequate model of care.

MiNDAUS Patient Registry will
1. enable patients, family carers and service providers to track disease progression and changing support needs,
2. facilitate direct consumer input to service design and evaluation.



The main areas of policy focus:
1. health literacy in MND,
2. care integration/models of care
3. improving access to services,
4. addressing workforce capability in MND care,
5. benefits of MND patients remaining at home.



Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration



ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/iafd20>

MiNDAUS partnership: a roadmap for the cure and management of motor Neurone disease

Steve Vucic, Naomi Wray, Anjali Henders, Robert D. Henderson, Paul Talman, Susan Mathers, Matthew Bellgard, Samar Aoun, Carol Birks, Gethin Thomas, Catherine Hansen, Geoff Thomas, Anne Hogden, Merrilee Needham, David Schultz, Tina Soulis, Bec Sheehan, Jane Milne, Dominic Rowe, Margie Zoing & Matthew C Kiernan

To cite this article: Steve Vucic, Naomi Wray, Anjali Henders, Robert D. Henderson, Paul Talman, Susan Mathers, Matthew Bellgard, Samar Aoun, Carol Birks, Gethin Thomas, Catherine Hansen, Geoff Thomas, Anne Hogden, Merrilee Needham, David Schultz, Tina Soulis, Bec Sheehan, Jane Milne, Dominic Rowe, Margie Zoing & Matthew C Kiernan (2022) MiNDAUS partnership: a roadmap for the cure and management of motor Neurone disease, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 23:5-6, 321-328, DOI: [10.1080/21678421.2021.1980889](https://doi.org/10.1080/21678421.2021.1980889)

To link to this article: <https://doi.org/10.1080/21678421.2021.1980889>

Website: <https://www.mindaus.org>

Galvin et al. BMC Health Services Research (2015) 15:571
DOI: 10.1186/s12913-015-1229-x

BMC Health Services Research

RESEARCH ARTICLE Open Access

Patient journey to a specialist amyotrophic lateral sclerosis multidisciplinary clinic: an exploratory study

M. Galvin^{1,2*}, C. Madden², S. Maguire^{3,2}, M. Heverin², A. Vajda², A. Staines¹ and O. Hardiman^{2,3}

Abstract
Background: The multidisciplinary approach in the management of Amyotrophic Lateral Sclerosis (ALS) has been shown to provide superior care to devolved care, with better survival, improved quality of care, and quality of life. Access to expert multidisciplinary management should be a standard for patients with ALS. This analysis explores the patient journey from symptom onset and first engagement with health services, to the initial visit to a specialist ALS Multidisciplinary Clinic (MDC) in Dublin, Ireland.

Open access Original research

BMJ Open Process evaluation and exploration of telehealth in motor neuron disease in a UK specialist centre

Esther Hobson^{1,2}, Wendy Baird³, Mike Bradburn⁴, Cindy Cooper⁴, Susan Mawson³, Ann Quinn⁵, Pamela J Shaw^{1,2}, Theresa Walsh^{1,2}, Christopher J McDermott^{1,2}

Check for updates

Alzheimer's/Dementia and Neuromuscular Disorders

The Role of Specialty Palliative Care for Amyotrophic Lateral Sclerosis

Anish Sethi¹, Elyse Everett, MD², Ambereen Mehta, MD, MPH³, Jessica Besbris, MD⁴, Christa Burke, MSW, LCSW, APHSW-C⁵, Elizabeth Pedowitz, MD⁶, Molly Kilpatrick, MD⁷, Laura Foster, MD⁸, and Sam Maiser, MD^{1,9}

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1-9
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Cordesse et al. BMC Health Services Research (2015) 15:134
DOI:10.1186/s12913-015-0810-7

BMC Health Services Research

RESEARCH ARTICLE Open Access

Coordinated care affects hospitalization and prognosis in amyotrophic lateral sclerosis: a cohort study

Valérie Cordesse¹, Florence Sidorok¹, Priscilla Schimmel¹, Josiane Holstein² and Vincent Meininger^{1*}

Abstract
Background: To determine whether an integrated approach to coordination of care influences hospitalization and clinical outcomes in a chronic neurological disease, amyotrophic lateral sclerosis.

Rapid Review Explores Best Practices of Integrated Models of Care in MND (in progress)

Collaborative study with Central Coast Local Health District, Central Coast, Central Coast Research Institute of Integrated Care, Macquarie University and University of NSW

Journal of Multidisciplinary Healthcare Dovepress
open access to scientific and medical research

Open Access Full Text Article REVIEW

Amyotrophic lateral sclerosis: improving care with a multidisciplinary approach

Anne Hogden¹, Geraldine Foley², Robert D Henderson³, Natalie James⁴, Samar M Aoun⁵

This article was published in the following Dove Press journal:
Journal of Multidisciplinary Healthcare
19 May 2017
Number of times this article has been viewed

Abstract: Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease, leading to death within an average of 2–3 years. A cure is yet to be found, and a single disease-modifying treatment has had a modest effect in slowing disease progression. Specialized multidisciplinary ALS care has been shown to extend survival and improve patients' quality of life, by providing coordinated interprofessional care that seeks to address the complex needs of this patient group. This review examines the nature of specialized multidisciplinary care.

PLOS ONE

RESEARCH ARTICLE

The path to specialist multidisciplinary care in amyotrophic lateral sclerosis: A population-based study of consultations, interventions and costs

Miriam Galvin^{1†*}, Pathraig Ryan^{2†}, Sinead Maguire³, Mark Heverin¹, Caoifa Madden¹, Alice Vajda¹, Charles Normand², Orla Hardiman^{1,3}

Abstract
Background: The multidisciplinary approach in the management of Amyotrophic Lateral Sclerosis (ALS) has been shown to provide superior care to devolved care, with better survival, improved quality of care, and quality of life. Access to expert multidisciplinary management should be a standard for patients with ALS. This analysis explores the patient journey from symptom onset and first engagement with health services, to the initial visit to a specialist ALS Multidisciplinary Clinic (MDC) in Dublin, Ireland.

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Background: To determine whether an integrated approach to coordination of care influences hospitalization and clinical outcomes in a chronic neurological disease, amyotrophic lateral sclerosis.

† Joint First Authors
* GALVINM@tcd.ie

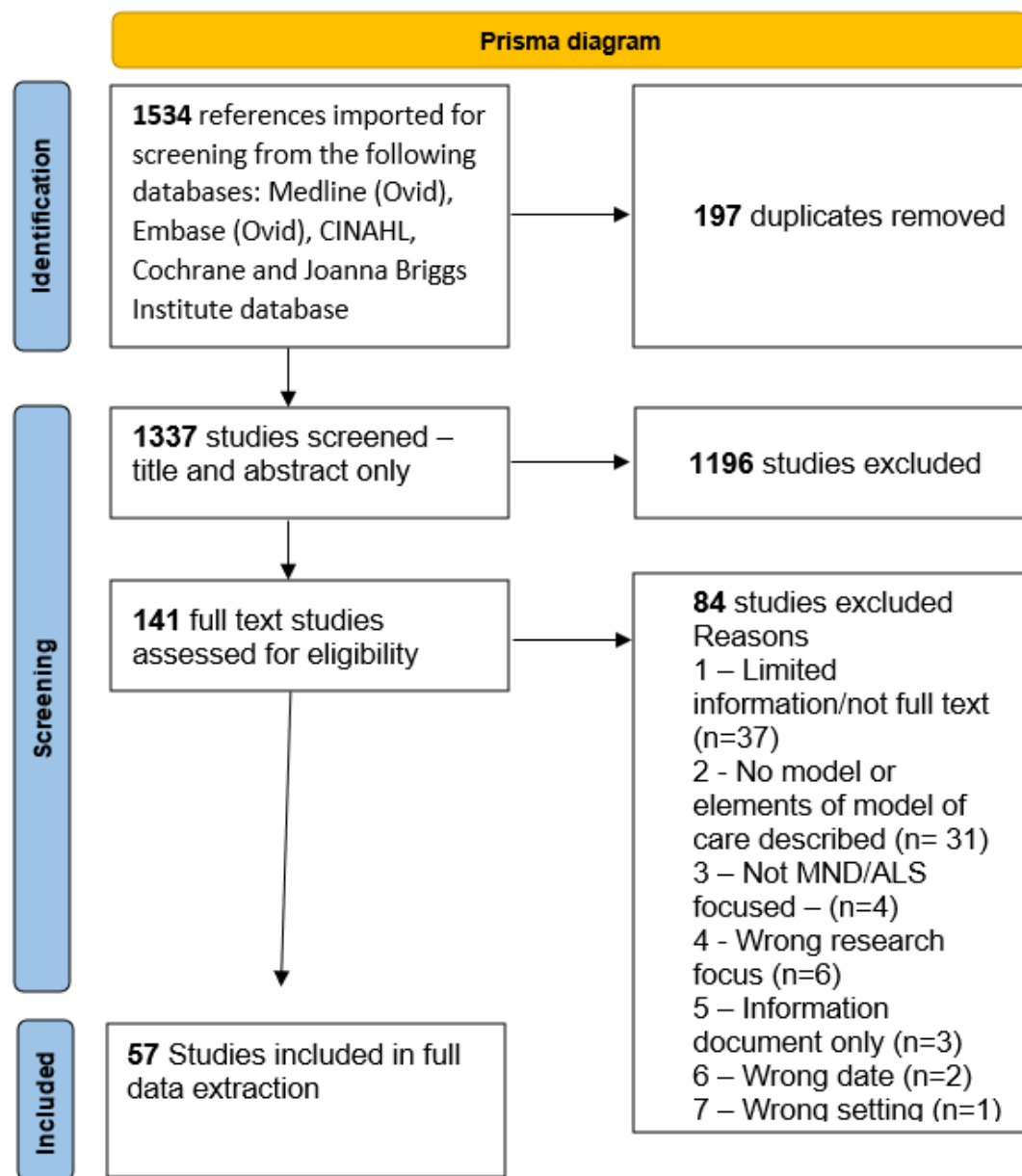
MULTIDISCIPLINARY AMYOTROPHIC LATERAL SCLEROSIS TELEMEDICINE CARE: THE STORE AND FORWARD METHOD

MICHAEL T. PULLEY, MD, PhD¹, REBECCA BRITAIN, RN², WAYNE HODGES, RN², CHRISTINE FRAZIER, RT³, LESLIE MILLER, ST⁴, MARIA MATYJASIK-LIGGETT, OT⁴, SUSAN MAURER, RD⁵, MELISSA PETERS, PT⁴, KIMBERLY SOLOMON, MSW⁶ and ALAN R. BERGER, MD¹

¹ Department of Neurology, University of Florida, Jacksonville, Florida, USA
² Department of Nursing, UF Health Jacksonville, Jacksonville, Florida, USA
³ Respiratory Therapy, UF Health Jacksonville, Jacksonville, Florida, USA
⁴ Rehabilitation Services, UF Health Jacksonville, Jacksonville, Florida, USA
⁵ Nutrition Services, UF Health Jacksonville, Jacksonville, Florida, USA
⁶ Department of Neuroscience, University of Florida, Jacksonville, Florida, USA

Accepted 11 May 2018

The aim of this rapid review is to identify models/ approaches to integrated care for plwMND through exploring the research literature in the area of MND and compare/ review particular models/component of models and how they contribute to more effective, efficient, person-centred integrated care practices across the continuum of care.



What the literature says about integrated models of care in MND?

No international standardised approaches in design and implementation, non consistency in the multidisciplinary workforce, and degree of integration and partnerships between hospitals and the community

Benefits

Coordinated, integrated interprofessional MND care:

- improves health outcomes
- improves resource use
- greater satisfaction with care for users and providers
- improves survival in MND which includes timely access to respiratory support and gastrostomy
- inclusion of palliative care services
- improves communication across organisations and sectors
- links with community based NIV and mechanical ventilation teams

Considerations



Distance to specialised MND clinics can be a barrier but telehealth technologies make this more accessible



MDTs need to consider stage and duration of MND and plwMND expectations, needs and priorities



Education opportunities for plwMND, families, health and social care providers

Health care access and need, and telehealth engagement

Collaborative study between St Josephs Hospital, MND service, MND NSW, University of NSW and Brain and Nerve Research Centre

STUDY

Exploring access to Motor Neurone Disease healthcare in New South Wales, and the potential use of Telehealth for patients in remote, rural and regional areas.

OBJECTIVES

- To confirm the **need for improved access to coordinated MND specialist healthcare** for those living in remote, rural and regional NSW.
- To report on the **areas of greatest clinical need**, as perceived by people living with MND.
- To report on specific **challenges or barriers faced by healthcare professionals** assessing or managing people living with MND.
- To understand the experience of, and willingness to engage in, a **specialist MND virtual health model**, for both people living with MND and healthcare professionals.

Regional MND specialist clinics

Collaborative study with Central Coast Local Health District, Central Coast, Central Coast Research Institute of integrated Care, Macquarie University and University of NSW

- **To evaluate the role and impact of a regional MND multidisciplinary clinic** in supporting coordinated and connected person-centred care across the care continuum from the perspectives of plwMND, their family members, and health and social care providers.
- **To examine the barriers and enablers to the implementation and sustainability** of an integrated MND multidisciplinary clinic on the Central Coast.
- To gather **information to inform design and development** of other regional MND clinic



Preliminary findings on implementation barriers and enablers

Enablers

- Access to clinic space
- Strong relationships and partnerships
- Excellent team knowledge and understanding of living with MND
- Access to administration staff
- Connection with plwMND and families
- Access to technology
- Engagement in research trials

Barriers

- Limited engagement by local public health district has impacted public health care professionals attendance
- Impacted by sector and funding silos
- Limited options for reimbursement of service
- Funding restraints impact developing the clinic further
- Limited capacity to run the clinic more frequently to meet demand

Communication and Decision making

1

Received: 5 September 2021 | Accepted: 6 June 2022
DOI: 10.1111/1460-6984.12757



International Journal of Language & Communication Disorders

RESEARCH REPORT

The impact of communication on healthcare involvement for people living with motor neurone disease and their carers: A longitudinal qualitative study

Camille Paynter¹ | Susan Mathers^{2,3} | Heidi Gregory^{2,4} | Adam P. Vogel^{1,5} | Madeline Cruice⁶

2

Article

Using the Concept of Health Literacy to Understand How People Living with Motor Neurone Disease and Carers Engage in Healthcare: A Longitudinal Qualitative Study

Camille Paynter^{1,*}, Susan Mathers^{2,3}, Heidi Gregory^{2,4}, Adam P. Vogel^{1,5} and Madeline Cruice⁶

¹ Department of Audiology and Speech Pathology, University of Melbourne, 550 Swanston Street, Melbourne, VIC 3010, Australia; vogela@unimelb.edu.au
² Calvary Health Care Bethlehem, 152 Como Parade West, Parkdale, VIC 3195, Australia; susan.mathers@calvarycare.org.au (S.M.); heidi.gregory@monash.edu.au (H.G.)
³ School of Clinical Sciences, Monash University, 246 Clayton Road, Clayton, VIC 3168, Australia
⁴ Eastern Health Clinical School, Monash University, 5 Arnold Street, Box Hill, VIC 3128, Australia
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* Correspondence: camille.paynter@unimelb.edu.au

3

doi: 10.1111/hex.12169

Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care

Anne Hogden PhD,* David Greenfield PhD,† Peter Nugus PhD‡§ and Matthew C Kiernan PhD¶

*Research Fellow, †Associate Professor, ‡Visiting Fellow, Centre for Clinical Governance Research, Australian Institute of Health Innovation, University of New South Wales, Sydney, NSW, Australia, §Assistant Professor, Centre for Medical Education and Department of Family Medicine, McGill University, Montreal, QC, Canada and ¶Bushell Professor of Neurology, Royal Prince Alfred Hospital, Sydney Medical School, University of Sydney, Sydney, NSW, Australia

4

Open access Original research

BMJ Open Gastrostomy uptake in motor neurone disease: a mixed-methods study of patients' decision making

Julie Labra ¹, Anne Hogden ², Emma Power,³ Natalie James,⁴ Victoria M Flood^{5,6}

Non-invasive Ventilation Uptake



Non-invasive ventilation (NIV) is currently the most effective therapy for extending life in motor neurone disease (MND), yet contemporary registry data suggest only 19% of Australians with MND ever try it.

Research Article | Original Research

Measuring Adherence to Long-Term Noninvasive Ventilation

Caroline Chao, David J Berlowitz, Mark E Howard, Linda Rautela, Luke A McDonald and Liam M Hannan
Respiratory Care September 2021, 66 (9) 1469-1476; DOI: <https://doi.org/10.4187/respcare.08745>

REPAIR MND - *Artificial Intelligence project aims to develop artificial intelligence software that can support the optimization of non-invasive ventilation for people with MND.*

Led by Professor David Berlowitz

Improving health outcomes in motor neurone disease by optimising the uptake of non-invasive ventilation - *aims to optimise quality of life and longevity of people living with MND, by specifically targeting improvements to the uptake of NIV.*

Led by Dr Marnie Graco - MNDRA Post-doctoral Fellow

NIV@home *will pilot whether using home NIV implementation and remote patient monitoring to substitute for day admissions and clinic attendance in people with disabilities is a feasible model for testing in a future, adequately powered, multi-centre study.*

Led by Professor David Berlowitz and Dr Nicole Sheers

Polysomnographic Titration of Non-invasive Ventilation in Motor Neurone Disease - *The aim of this trial is, in people with MND who are referred for NIV, to investigate whether polysomnographic titration of NIV during set-up will improve NIV usage*

Multi-centred RCT led by Professor David Berlowitz

Non-invasive Ventilation



Non-invasive ventilation (NIV) is currently the most effective therapy for extending life in motor neurone disease (MND), yet contemporary registry data suggest only 19% of Australians with MND ever try it.

REPAIR MND - Artificial Intelligence project aims to develop artificial intelligence software that can support the optimization of non-invasive ventilation for people with MND.
Led by Professor David Berlowitz

Project aims to:

1. obtain an accurate estimate of the current rate of NIV uptake in the Australian MND population, and identify factors that predict uptake (a national survey)
2. understand the barriers to NIV uptake from the perspective of people living with MND, their carers / family and clinicians (a qualitative study)
3. design an adaptable implementation strategy that targets these barriers to increase NIV uptake (using co-design principles)
4. implement and evaluate the effectiveness of this strategy in a single Australian location (a pilot implementation study)

NIV@home will pilot whether using home NIV implementation and remote patient monitoring to substitute for day admissions and clinic attendance in people with disabilities is a feasible model for testing in a future, adequately powered, multi-centre study.
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Research Article | Original Research

Measuring Adherence to Long-Term Noninvasive Ventilation

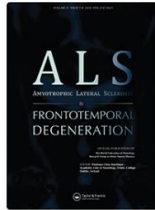
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Focus on Palliative care and Caregivers research

 Palliative Care & Social Practice

Why and how the work of Motor Neurone Disease Associations matters before and during bereavement: a consumer perspective

Samar M. Aoun , Paul A. Cafarella , Anne Hogden , Geoff Thomas, Leanne Jiang  and Robert Edis



ALS
Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration


Taylor & Francis
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ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/iafd20>

Grief, depression, and anxiety in bereaved caregivers of people with motor neurone disease: a population-based national study

Samar M Aoun, David W Kissane, Paul A. Cafarella, Bruce Rumbold, Anne Hogden, Leanne Jiang & Natasha Bear

To cite this article: Samar M Aoun, David W Kissane, Paul A. Cafarella, Bruce Rumbold, Anne Hogden, Leanne Jiang & Natasha Bear (2020) Grief, depression, and anxiety in bereaved caregivers of people with motor neurone disease: a population-based national



Progress in Palliative Care
Science and the Art of Caring

Taylor & Francis
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ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/yppc20>

Compassionate community connectors: a distinct form of end-of-life volunteering

Kerrie Noonan, Bruce Rumbold & Samar M. Aoun

To cite this article: Kerrie Noonan, Bruce Rumbold & Samar M. Aoun (2022): Compassionate community connectors: a distinct form of end-of-life volunteering, Progress in Palliative Care, DOI: [10.1080/09699260.2022.2090051](https://doi.org/10.1080/09699260.2022.2090051)

To link to this article: <https://doi.org/10.1080/09699260.2022.2090051>

Healthcare research needs you as partners to make changes

Participants

Health and social care providers, health care managers, people living with MND, family members including children, community groups etc

Range of methodology

Interviews, focus groups, surveys, random controlled trials, observation studies, pilot intervention studies, stakeholder advisory groups, retrospective studies, reviews, medical record reviews etc

**Working together to
improve care experiences
living with MND**

Thank you

Contact Karen Hutchinson: karen.hutchinson@mq.edu.au