

**The right to rehabilitation for people with
dementia: Implementation and evaluation of
the “INCLUDE” interventions**

Protocol for Stage 2

Funding: MRFF 2021 Dementia, Ageing and Aged Care
Mission

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2. BACKGROUND

Short Summary

People with dementia experience stigma which impacts all aspects of their lives, including health outcomes and quality care. There is a tendency to equate dementia with severe physical and mental incapacity, and the inability to engage or benefit from treatments. This is not necessarily the case. Two thirds of people with dementia live in the community, of whom many are supported by care partners and aged care services¹.

Systematic reviews and randomised control trials²⁻⁶ found rehabilitation treatments improve activities of daily living and quality of life, especially if delivered early in the condition. Clinical practice guidelines specifically recommend people with dementia should be referred to allied health professionals (AHP) to maintain/improve function for as long as possible⁷⁻⁹. Importantly rehabilitation also reduces care partner stress, a major driver of admission to aged care¹⁰. Reducing disability associated with dementia could save on the \$3 billion spent directly on health and aged care (2018-2019 figures), by keeping people with dementia at home for longer and ensuring they lead meaningful lives¹¹. However, rehabilitation is often denied to people living with dementia¹²⁻¹⁴. Not providing rehabilitation is a huge gap and missed opportunity to extend independence and wellbeing.

Rehabilitation is a national and international priority. The Royal Commission into Aged Care (RCAC) recommended that rehabilitation be a central focus to maintain or improve older people's physical and cognitive capabilities, support their self-determination, and facilitate people to remain at home for as long as possible¹⁵. The Australian Commission for Safety and Aged Care Standards state that organisations should provide care to optimise wellbeing and independence and that the workforce should be skilled and trained to do so¹⁶. The World Health Organization's global action plan in response to dementia (2017–25) specifically calls for member states to develop pathways of efficient and coordinated care that include rehabilitation to address disability¹⁷.

Members of Dementia Alliance International reported that experiences of people with dementia with rehabilitative treatments are almost non-existent. There are barriers and challenges at multiple levels: 1) *Health professional stigma* about the value of rehabilitation for people with dementia and their ability to engage in therapy^{14, 18} 2) *Low levels of knowledge* about the evidence for dementia rehabilitation exist^{14, 18}, which is also likely to contribute to stigma, 3) *People with dementia and their carer partners* find services hard to navigate¹⁹ and report needing information to empower them to ask for rehabilitation and support to access it²⁰, 4) *No clear model or pathway* in the system for providing rehabilitation for people with dementia¹⁹. Given the evidence for rehabilitation interventions to reduce disability and improve wellbeing in people with dementia, there is much need in addressing stigma and overcome challenges to promote rehabilitation access for people with dementia.

Rationale

There is evidence for rehabilitation interventions to reduce disability and improve wellbeing. Co-design workshops have been held to determine strategies to address stigma and challenges to rehabilitation access for people with dementia. A package of solutions "INCLUDE", will be developed by the research team and/or our partners. We will test and evaluate their implementation in improving access to rehabilitation, improving knowledge and reducing stigma.

This protocol described the implementation and evaluation of the "INCLUDE" solutions (Stage 2).

The INCLUDE solutions are:

1. A dementia rehabilitation e-module for health professionals
2. Dementia Training Australia education for GPs
3. A dementia rehabilitation community of practice for health professionals
4. Dementia rehabilitation resources to support referrers, providers and people with dementia and their care partners

Solutions that have been implemented by our partners include:

1. SEMPHN and EMPHN dementia health pathways
2. SEMPHN Dementia rehabilitation program

Other proposed outputs include:

1. Updating the Dementia Australia guide for people with dementia and their care partners to include greater information about allied health.

3. PURPOSE OF THE STUDY

Stage 2 aims

The specific aims are to determine:

1. The number, type, work setting and proportion of GP practices, GPs, practice nurses, AHPs and other professionals who agree to participate in the study and partake in any of the INCLUDE solutions
2. The effect of the INCLUDE solutions on change in stigma and knowledge about dementia rehabilitation
3. The effect of the INCLUDE solutions (e-module and community of practice) on change in:
 - a. social networks
 - b. number of people seen with dementia by allied health professionals and
 - c. number of advocacy actions and changes to practice by members in their workplace
4. Acceptability, satisfaction and perceived sustainability with the INCLUDE solutions
5. The number of people with dementia referred by GPs to allied health pre and post intervention (using GP data extracted with the POLAR tool) **[Please note this is a separate ethics application to be submitted]**
 - a. Compare the proportion of people with dementia referred to allied health at baseline (from 2018-December 2022) to during the 12m intervention period (October 2023-2024) by primary health network and also by those GP practices/GPs in the intervention to those not in the intervention
 - b. Compare the pre-post proportion of people with dementia referred to allied health compared to age and sex matched older people and other neurological conditions (e.g. Parkinson's Disease)

4. METHODS

Design

Implementation study with a pre-post, mixed method design, combining qualitative and quantitative methods. The implementation period will be 12 months in duration.

Setting

The project will be conducted in the East Melbourne and South East Melbourne primary health networks.

Participants and recruitment

Health professional (no limit on numbers) will be recruited in East Melbourne and South East Melbourne primary health networks. This includes health professionals from community rehabilitation programs, community health services and multi-disciplinary cognitive clinics of health services (e.g. Eastern Health, Monash Health, and Peninsula Health), community aged care providers, and private practices who have an interest in gerontology. Dementia Support Specialists, NDIS, RAS and ACAT assessors and co-ordinators in the local area will also be invited. Advertising will take place through direct contact (emails, phone, letters, advertising through CIs health service contacts) with managers or individual clinicians.

GP practices (GPs and practice nurses) will be recruited through East Melbourne and South East Melbourne primary health networks via PHN newsletters, social media, direct contact (phone, email, letter, in person meetings) and research networks of the CIs.

Geriatricians, Neurologists and Older age Psychiatrists based in geriatric medicine and cognitive outpatient clinics in major health services in East and South East Melbourne will also be invited to participate.

Inclusion Criteria

Located in East Melbourne, South East Melbourne primary health networks; and 2) Likely to stay at the practice for 12 months

INCLUDE solutions

From the co-design phase, the “INCLUDE” solutions will include the following components:

1. An on-line training module ‘What is dementia rehabilitation and the role of the allied health professional’. Topics will include the evidence for rehabilitations, barriers to access and ways participants can address some of the barriers.
2. Dementia Training Australia (DTA) run a diagnosis and managing dementia training session 1.15 h x 3 webinars or 6 hours face to face – this will be evaluated as part of this study.
3. A Community of Practice (CoP) with the aim to improve interdisciplinary knowledge and dementia rehabilitation expertise, enhance collaboration between members and advocate for people with dementia being able to know about and access allied health.
Components of the CoP may include:
 - a. Access to members details to facilitate referrals and networking

- b. Webinars
 - c. Digital newsletter with AH related topics and research updates
 - d. Question and discussion board
 - e. Region/satellite face to face and/or online meetings
 - f. Resources
 - g. A power-point that can be used to inform and educate others of the role of allied health in dementia
4. Resources to be provided during 1-3:
- a. An 'Allied health and dementia' brochure
 - b. A decision support and communication tool to help referrers understand and select allied health professionals for their clients, and illustrated by case studies

Allied health professionals, nurses, and other professionals who commence participation at the beginning of the 12-month study (around Oct/Nov 2023), will be invited to participate in all aspects of the INCLUDE solutions,

For allied health professionals, nurses, and other professionals who commence participation in mid-study (May 2024), they will be invited to participate in the e-module only.

Measures

Characteristics: Age, gender, profession, work setting, working hours per week, work experience in years, postgrad training, self-perception of expertise in dementia care

1. The number, type, work setting and proportion of GP practices, GPs, practice nurses, AHPs and other professionals who agree to participate in the study and partake in any of the INCLUDE solutions (e-module, community of practice webinars/discussions, Dementia Training Australia (DTA) education)
2. Pre-post INCLUDE solution change in stigma and knowledge about dementia rehabilitation (e-module, community of practice and DTA education)

All participants will complete a pre and post questionnaire administered via REDCap/Qualtrics platform or hardcopy. This includes the General Practitioner Attitudes and Confidence Scale (GPACS–D) for dementia (or the Dementia Attitudes scale for other professionals), and an investigator designed dementia rehabilitation questionnaire (based on current evidence) and the Dementia Knowledge Assessment Scale questionnaire. These questionnaires will be administered at baseline, after the e-module and at 12 months. GPs and practice nurses attending the DTA training will be asked to complete the questionnaires pre and post DTA training and after 4 months.

3. Pre-post outcomes of the community of practice will be measured using a questionnaire:
 - a. *Social networks and collaboration:* Direct working relationships and connections with other therapists will be measured pre and post the intervention (by PHN area) The questionnaire on the direct working relationships will list the names of all participants. Participants will be asked to tick a box for each name indicating whether this person was known to the participant and another box to indicate whether this person is involved in professional contact. Knowing each other is defined as ‘knowing the face, having talked to each other, or having heard of’. Professional contact is defined as ‘having had professional contact about at least one patient, including referral letters, e-mail, telephone and face-to-face consultation’
 - b. number of people seen with dementia by allied health professionals
 - c. and number of advocacy actions and changes to practice by members in their workplace
4. Acceptability, satisfaction and perceived sustainability with the INCLUDE solutions will be measured with a survey and questions rated on an ordinal scale immediately post the e-module and at 12 months for the community of practice (including webinars and resources). A focus group will be used to determine the acceptability and usefulness of the education run by Dementia Training Australia 4 months post training.
5. Uptake: Proctor defines uptake as the integration of practice within a service setting and its subsystems.
For GP’s: a change in their referrals to AHPs for people with dementia measured via the Population Level Analysis and Reporting (POLAR) primary healthcare network database already available in > 300 GP practices in the East and South East Melbourne Primary Health Networks (this will be applied for in a separate ethics application)
Specifically, we will examine:

- c. Compare the proportion of people with dementia referred to allied health at baseline (from 2018-December 2022) to during the 12 month intervention period (October 2023-2024) by primary health network and also by those GP practices/GPs in the intervention to those not in the intervention
- d. Compare the pre-post proportion of people with dementia referred to allied health compared to age and sex matched older people and other neurological conditions (e.g. Parkinson's Disease)

The assessment of “uptake” by analysing GP data using the POLAR tool will be submitted in a separate ethics application to MUHREC.

For AHPs, this would be the self-reported change in the number of patients with dementia for the 12-month period.

Data analysis

Descriptive statistics will be used to:

1. describe the characteristics of participants, their work-setting and experience.
2. describe the number of each profession who agree to participate, and how many partake in each of the INCLUDE solutions.

Attitudes and knowledge: Change in pre and post intervention stigma, knowledge will be analysed using paired samples t-test or the signed ranked test.

Acceptability, sustainability and satisfaction: will be described using summary statistics or for open ended questions with content analysis. For focus group data, researchers will transcribe the focus group recordings, and thematic analysis will be used to analyse the data.

Social networks and collaboration: Data will be entered into a squared data-matrix with the health professionals in the rows and columns and values in the cells to indicate presence or absence of connection (1,0). The first stage of data analysis will focus on the total network and the area-specific networks. The second stage of data analysis focused on the networks of the individual health professionals ('ego networks'). These individual networks will be extracted from the total network for each health professionals, including the reported connections of the individual with others in the network and the connections between those others.

Uptake: Change in referral proportions over time will be investigated via interrupted time-series analysis, comparing both the outcome level (observed proportions) and slopes (rate of change in proportion) over time. The time series will be comprised of data from the *control* phase utilising both the 12m prior to the preparation phase (primary) and the longer-term trends from 2018 (secondary) and over the intervention 12-month implementation period.

5. OUTCOMES OF THE STUDY

The outcome will be a comprehensive, evidence informed and interdisciplinary implementation package of solutions. It will have a set of resources developed for promoting rehabilitation, facilitating referrals and access to rehabilitation for people with dementia. It will help to reduce stigma, ensure knowledge and connect health professionals, which provides support and access to best practice rehabilitation for people with dementia.

6. Data security and handling

Electronic survey data files. Access to the survey datasets will be restricted to the CIA and research staff who have log-on and a secure password to the data files. The on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. After this time, the data will be destroyed. The storage and the destruction of data will adhere to Monash University regulations.

Hard copy of surveys . Once the data is collected and transferred to electronic databases, the hard copies will be destroyed. The storage and the destruction of the hard copies will adhere to Monash University regulations.

Audio/video recordings will be deleted after focus group transcription is completed. Access to the interview transcripts will be restricted to the CIA and research staff who have log-on and a secure password to the data files. The on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. After this time, the data will be destroyed. The storage and the destruction of data will adhere to Monash University regulations.

All access to the data during the study will be restricted to the research team and upon approval by the CIA. Access to data after the project is completed will be restricted to the research team and with a relevant ethics approval.

The final report, and any resulting conference, journal publications or presentation will only contain results from participant responses that are aggregated or individual responses de-identified.

7. Ethics and ethical issues

Stage 2 of this project will seek ethics approval from the Human Research Ethics Committee of Monash University and site governance of Monash Health, Eastern Health and Peninsula Health.

A separate ethics application will be made to the Monash Uni HREC for use of the POLAR dataset. We will obtain a data transfer agreement between Monash University, Outcome Health, Eastern and South Eastern Melbourne Primary Health Networks.

Consent and withdrawal process

Participation in Stage 2 is voluntary. All participants will be provided with a plain language information sheet and consent form (for the implementation and evaluation of “INCLUDE”). They can contact Dr Angel Lee to clarify any issues before they sign the consent form. Referrers and providers will return the consent form to the researcher before stage 2 begins.

They may withdraw from “INCLUDE” at any time by notifying Dr Lee as soon as possible. There will be no follow-up by the research team for withdrawal nor implications of withdrawal. The information that was collected from the participants up to the time they withdraw from “INCLUDE” will be used to inform Stage 2 findings and cannot be withdrawn.

Confidentiality

Any information obtained in connection with “INCLUDE” implementation and evaluation that may identify the participants will be de-identified. Any journal publications or conference papers will only contain results from responses that are grouped or individual response de-identified.

Possible benefits and risks to participants

Referrers and providers may benefit from having access to dementia-specific rehabilitation resources, training, and formed provider network that would enhance care to patients with dementia.

We do not foresee any risks to referrers, providers and people with dementia in taking part in “INCLUDE”. However, there may be a slight risk that the co-designed resources or training provided may not suit the needs of a particular health professional. In this case, we will direct them to their professional body and Dementia Australia for further assistance.

8. Plans for return of results to participants

Scientific/clinical community

This will be made available by research publications and conference presentations.

Key stakeholders

This will be made available via a brief summary report provided on the National Centre for Healthy Ageing (NCHA) website.

General community including participants who request a summary of outcomes

A plain language summary (de-identified) will be provided on the NCHA website and forwarded to any participants requesting a copy.

9. Plans for dissemination and publication of project outcomes

All resources will be publicly available and promoted by our team and partners through social media and organisation websites, including Dementia Australia. Our team and partners will disseminate 1) the project findings and INCLUDE package and 2) advocate for uptake nationally, through workshops in each state and territory.

10. Timeline

MRFF Month number	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	
	0	0	0	0	1	1	1	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	0	0	0	0	0	
	6	7	8	9	0	1	2	1	2	3	4	5	6	7	8	9	0	1	2	1	2	3	4	5	6	7	8	
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	3	3	3	3	3	3	3	4	4	4	4	4	4	4	4	4	4	4	4	5	5	5	5	5	5	5	5	
Approval obtained from Monash Human Research Ethics Committee - Phase 2																												
Finalise E-module and training content																												
Develop and refine written resources / tools																												
Recruit participants: Allied Health, GPs and other referrers																												
Complete baseline knowledge, stigma and practices survey data collection																												
DTA pre-training survey																												
DTA GP / nurse training within PHN																												
DTA post-training survey																												
E module (and CoP) pre-training survey (1 st intake)																												
Launch E-module (1 st intake)																												
E-Module post-completion survey (1 st intake)																												
Launch Community of Practice (CoP)																												
Ongoing maintenance of CoP																												
DTA focus group and survey																												
E module pre-training survey (2 nd intake)																												
Launch E-module (2 nd intake)																												
E-Module post-completion survey (2 nd intake)																												
12-month survey for e-module (and CoP) 1st intake																												
Complete intervention phase																												

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