Dementia day programmes in the community: A New Zealand case study update

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Abstract
Globally dementia day programmes play an increasingly important role in supporting the wellbeing of both older people living at home with dementia and their caregivers. Typically day programmes provide psychosocial and/or physical health functioning benefits to members, as well as respite for caregivers. To ensure day programmes deliver on these aspirations, service providers regularly review services offered to older people. This article provides an update on the outcomes of the original New Zealand small-scale pilot case study aimed at investigating the elements that make up an effective client-focused dementia day programme. The study also focused on methods employed to measure the quality of outcomes of day programmes.

The original research reported in 2015 utilising mixed methods revealed that effective day programmes comprised five core elements: 1) activities aimed at improving client functioning 2) caregiver benefits 3) workforce capability 4) cultural responsiveness 5) service processes. Reporting and auditing processes as well as surveys are reportedly used as methods to measure the quality of outcomes of day programmes.

In 2017 follow-up semi-structured interviews were undertaken with several key stakeholders from the service provider to determine the progress that had been made in relation to the five core elements and their relevance to future planning. Interviews also focused on how they were measuring the quality of their day programmes. The findings highlight successes and challenges around implementing the five core elements that constitute effective day programmes and may inform debate internationally and lead to better outcomes for both those living with dementia and their caregivers.
1.0 Introduction

Aotearoa New Zealand faces the same global challenge of many western countries; an ageing population with an increased demand on services for older people. Internationally there continues to be considerable improvements in health care and living standards, both of these factors have contributed to people living longer and consequently this is challenging health and social services [1]. A shift in demographic patterns at the older end of the age continuum has amongst other things has seen an increased number of clients requiring access to dementia-related services. It is estimated that 46.8 million people worldwide are living with dementia and that this number is likely to increase to 131.5 million in 2050 [2].

Dementia is not a single disease, it is caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities, and is usually of a chronic progressive nature [3]. Dementia is a costly condition from its social, economic, and health dimensions, as a response to this concern an increasing number of countries have developed strategies and policies that are designed to support people living with dementia to remain longer at home in their communities[1].

Day programmes provide an important aspect of the care continuum supporting the wellbeing of both older people living with dementia and their caregivers. Day services can be divided into three models: the medical model, the social model, and the combined model [4]. Programmes operating under the medical model include skilled assessment, treatment, and rehabilitation goals. The social model programmes focuses on socialization and preventive services whilst a combined model has elements of both a social and medical programme, depending on individual client needs [4]. Despite these categories, there are significant within-model variations in service delivery and a range of intervention-specific studies document the impact or effectiveness of particular interventions offered as part of a day service.

Over the past few years a number of studies have focused on the perceived benefits and effectiveness of day programmes. In 2014 four key themes were identified in a qualitative study undertaken in Norway with a group of home-dwelling persons with early onset dementia attending an activity centre [5]. The four themes were that participants: 1) Appreciated the range of activities. 2) Praised the nurses and volunteers for their support. 3) Enjoyed being more physically active. 4) Felt included in a fellowship [5].

A small qualitative study undertaken in 2015 in the Netherlands investigated what factors enabled a smooth transition from one kind of day centre (nursing home-based) to another (community-based) as well as the advantages of community-based day centres over nursing home based[6]. These included the added value of the combined support programmes available at the community centres (consisting of cognitively stimulating activities and psychomotor therapy), the way they helped carers as well as dementia sufferers, increased opportunities for social integration, regular meetings and discussion groups for carers where they could express their feelings, plus economic benefits [6].

A Japanese study reported in 2017 investigated over several years how participating at a community centre affected cognitive health of older people. This statistical study found that participation was associated with a lower likelihood of cognitive decline. “Frequency of salon (day programme) participation was protectively associated with cognitive decline, even after adjusting for time-dependent covariates and attrition (odds ratio =0.73, 95% Confidence Interval 0.54-0.99)” [7].
There are a myriad of organisations globally which offer community-based day programmes for elderly people who have been diagnosed with dementia and respite for their caregivers. A common characteristic shared by these organisations is that they are not-for-profit organisations or charitable trusts that are intrinsically connected to their respective communities through the services they have provided over a number of years. Funding for the day programmes are obtained through sources that include state funding, private client fees, bequests, donations and contributions in the form of volunteer work. It is this context that this current update of the original research reported in Dementia in 2015 was undertaken [8]. The focus of the original research was on a day programme regarded as a non-residential day service utilising a social care model and although based in the community, excluded home-based services. Two overarching research questions guided the original project:

1. What are the elements that make up an effective client-focused day programme for people living with dementia?
2. What are the methods employed by organisations to measure the quality of outcomes of their day programmes?

2.0 The New Zealand case study update

This section presents the New Zealand context and current dementia policy environment within which the case study update was undertaken. Background to the original research is provided in the next section followed by background on the 2017 update.

2.1 New Zealand current policy environment

In order to highlight the need for resources and growing costs of providing services to people living with dementia and their caregivers, Alzheimers New Zealand commissioned Deloitte to produce an ‘Economic Impact of Dementia’ report [9]. The most recent report suggests there will be approximately 170,000 New Zealanders living with dementia by 2050, up around 300 percent on current figures of 62,000. Costs of supporting dementia diagnosed people are projected to reach nearly $5 billion by 2050. It is suggested that new models of care that delay entry into residential care have the potential net benefit of $22 million a month leading to substantial savings over time. The economic impact report is a key information source on the size and scale of the dementia challenge in New Zealand and is used to inform decision-making around dementia policy [9].

The New Zealand policy framework for care of the older person is primarily based on two key Government strategy documents: ‘Positive Ageing Strategy, 2001’ Ministry of Social Development, and the Ministry of Health’s ‘Health of Older People Strategy, 2002’. The Positive Ageing Strategy promotes the concept of positive ageing, affirms the value of older members of society, and highlights the importance of issues such as access to health services, financial security, independent living, the physical environment and personal safety. The Health of Older People Strategy details an integrated continuum of care, which seeks to ensure that all relevant health and disability services are coordinated in such a way that older peoples’ needs are appropriately met [10].

In recognition of escalating numbers of older adults diagnosed with dementia, the New Zealand Ministry of Health released in 2013 the ‘New Zealand Dementia Care Framework’ to initiate and coordinate dementia services for people living with dementia in the caregivers/families [11]. The Framework actively promotes community-based services that support
those individuals living with dementia to remain living at home and day programmes are a component of this approach [11].

2.2 Background to the original research

Impact Research NZ was commissioned by Presbyterian Support Northern (PSN) to investigate the elements that make up an effective client-focused day programme for people living with dementia and the methods employed to measure the quality of outcomes of day programmes. Enliven is a division of PSN and offers a range of services for the older person including delivering day programmes to cater for people living with dementia and support for their caregivers.

2.2.1 Study setting

The original research was undertaken in collaboration with PSN, a large social service provider offering a range of services for children and families, people with disabilities and older adults including home support. PSN offers day programmes for older adults through Enliven, a service division. The community-based day programmes are offered at five sites in the upper North Island. The research sites selected were one in Hamilton with a mainly European and Māori population and one in South Auckland with a mainly Pasifika, Māori and European population. Funding for day programmes is through District Health Boards (DHBs).

2.2.2 Methodology

In the original study a mixed methods approach was employed including: an international literature review, document analysis, interviews, focus group, online surveys, site observations, and a photovoice exercise. Participants included multiple stakeholders: service funders, service providers, clients and their caregivers – all of them signed a consent form outlining their rights and were provided with an information sheet about the project and what would happen with the findings. The international literature review focused on existing day programmes for older people living with dementia with the aim to identify common elements of effective programmes and measures utilised to assess outcomes as a context for the findings from the study.

A day in the life of a client living with dementia was captured through a photovoice exercise. A total of eight clients (four males and four females) consented. Drivers, caregivers and support workers involved with the participating clients on the day, also contributed to the photovoice exercise. The unstructured site observations provided the research team with an opportunity to meet some of the clients and staff on-site and to record clients’ experiences from a participatory perspective. Caregivers and support workers completed a brief questionnaire – a total of 32 completed questionnaires were analysed. Three team leaders, four caregiver participants and two drivers from each day programme participated in the telephone interviews, while two support workers from each site participated in face-to-face interviews. Face-to-face interviews were also conducted with representatives from the Counties Manukau and the Waikato District Health Boards: the PSN General Manager for Enliven Services and the two area managers of both day programmes. The data from all the face-to-face individual interviews as well as the recorded telephone interviews were combined and analysed using inductive thematic analysis.

2.2.3 Summary of key findings from the original research
The original research reported in 2015 revealed that effective day programmes comprised five core elements including: activities aimed at improving client functioning; caregiver benefits; workforce capability; cultural responsiveness; and service processes [8]. Reporting and auditing processes as well as surveys are reportedly used as methods to measure the quality of outcomes of day programmes [8]. These findings are elaborated in the next section.

2.3 2017 research update

2.3.1 Objectives

1) To explore what progress had been made by PSN in relation to the five core elements and determine their relevance to future planning.

2) To identify current practices for measuring the quality of day programmes.

3) To identify trends observed around dementia care

2.3.2 Methodology

Semi structured face-to-face or telephone interview were undertaken. Face-to-face interviews were undertaken with key stakeholders.

2.3.3 Sample

Several key PSN stakeholders were identified to interview: the Chief Executive Officer, General Manager Enliven, General Manager Development, Enliven Clinical Practice Leader (newly created appointment in since the original research), Enliven Quality Manager and Enliven managers.

2.3.4 Ethics/consent

All participants were provided with an information sheet outlining the purpose of the evaluation update, right to withdraw, data security and how the information would be used.

2.3.5 Analysis

The data from all the face-to-face individual interviews as well as the recorded telephone interviews were combined and analysed using inductive thematic analysis.

2.4 Key findings from the original research and updated results

The findings from the original research are presented here first and in two parts. The first part focuses on common elements that make up an effective day programme. The second part focuses on methods to measure the quality of outcomes. The follow-up research results are presented after the original research finding in each part.

2.4.1 Elements that make up an effective client-focused day programme

Original research finding

Common elements of day programmes derived from the document review were considered alongside relevant literature and findings from the data to inform research question 1: What are the elements that make up an effective client-focused day programme for people living with dementia? Five main elements were identified. It wasn’t in the scope of the study to evaluate the actual effectiveness of these elements, but these elements are considered core to what people perceive an effective day programme should comprise [8]. These are:

1) Activities aimed at improved client functioning

2) Caregiver benefits

3) Workforce capability

4) Cultural responsiveness

5) Service processes
Each of these elements is described below followed by an update on progress against that element.

2.4.1.1 Activities aimed at improved client functioning

Effective day programmes are client focused, contribute to the development of a sense of security, encourage engagement with the programme through a range of activities and generally ensure that the person living with dementia experience a range of psychosocial benefits through their participation in the programme.

Update

Research interviewees noted the ongoing challenge of ascertaining the right mix of activities for day programmes that provide cognitive stimulation for clients based on research evidence and also the extent to which individual cognitive function is also evidenced. Enliven has commissioned further research to address these challenges and appointed a Clinical Practice Leader who among other duties takes the lead in developing an eight year dementia strategy.

Range of activities

Enliven day programmes continue to offer a wide range of social and physical activities aimed at improving client functioning. Currently Enliven is exploring how to incorporate cognitive stimulation therapy into their day programmes. Cognitive stimulation therapy (CST) is a structured group therapy for people with mild to moderate dementia [12]. Enliven managers increasingly utilise research to inform the choice of activities to ensure they meet client needs. These activities are designed to be done either independently (e.g. reading a newspaper), in small groups (e.g. conversations) or with a larger group (e.g. singing or physical exercise sessions). Client interest and individualised support plans help determine which activities take place. Popular activities with clients are: outings in the community e.g. to the local lake, art galleries, museum; cooking, art and crafts, gardening, shopping, music therapy e.g. ‘Music Moves Me’ (provides mental stimulation, dancing and exercise), picnics and barbeques, going for walks, sports such as petanque, indoor and outdoor bowls, cultural events and a non-alcoholic cocktail hour.

One day programme continues to offer their male and female clients gender-based activities in the smaller women’s unit and the Bloke’s Club – this approach has been reported to be effective in meeting its desired outcomes of being client driven. Another day programme is located adjacent to a childcare centre that welcomes day programme clients to interact with the children in meaningful activities – this approach has been reported as being mutually beneficial to both the clients and the children who appear to enjoy the intergenerational conversations and activities.

Psychosocial benefits and sense of security

Enliven is more strongly focused on identifying the psychosocial benefits for clients which includes helping them to feel secure at the day programme. There is an emphasis on building positive relationships with clients and their caregivers. Increasing numbers of clients attend daily to fit in with the working week for the caregivers. The following psychosocial benefits were identified by the research interviewees based on their observations and client and caregiver evaluations:

- Increase connections with community
- Regain ability to undertake daily activities- thinking about lunch, going shopping and cooking
- Forge friendships and build camaraderie and are supportive of each other
- Reduction in loneliness
- Sense of belonging
• Enjoy being part of a group/team
• Feel valued by day programme staff
• Do not feel they are there because they have a problem
• Able to talk freely and relax

2.4.1.2 Caregiver benefits

Original research finding
Effective day programmes include a focus on caregivers to enable: participation in work and leisure activities, a reduction in stress and potentially capability to support the client better as to delay institutionalisation.

Update
Caregiver respite is considered to be an important feature associated with Enliven day programmes. The caregivers of clients are provided with an opportunity to have a meaningful break from the challenges that come with looking after a spouse or family member who has been diagnosed with dementia. Research interviewees noted that Enliven continues to work on improving its communication with caregivers and sees this as an ongoing challenge to get the right balance.

“I think one of the key things I remember from the earlier research was about how do you provide feedback to the caregiver to know what their loved one has been up to. So a piece of work we are looking at doing is introducing the ‘Te Whare Tapu Whā’ model for all Enliven and in particular the day programmes.”

Research interviewees identified the benefits of day programmes to caregivers:
• Allows caregivers to have time out and relieves stress of every day care
• Allows caregivers who are working to continue working
• Provides peace of mind that the clients are taken care of
• Enables caregivers to seek advice on various aspects associated with the care of their loved one
• Able to witness incremental improvements in their loved one’s ability to function
• Able to witness their loved one’s responses under different circumstances when they visit the day programme
• Ability to stay connected the community.

2.4.1.3 Workforce capability

Original research finding
Effective day programmes employ staff that are well-trained and knowledgeable about dementia, possess key qualities, including the ability to build and maintain relationships, and clarity about their duties and expectations to manage challenges.

Update
There have been two key influences on the workforce development for Enliven staff who work in day programmes. The first influence was the national debate around remuneration for support workers who are predominantly female. As a consequence
of the Terra Nova court case which successfully argued a caregiver’s remuneration would be less than paid to a male with the same skill set in a different occupation, the Government was called to action [14]. In April 2017, the Government announced a $2 billion pay equity settlement for 55,000 care and support workers in the aged and disability residential care and home and community support services. The agreement established a matrix of pay rates, linked to a qualification structure, to be phased in over the 5-year term of the agreement [14].

The second key influence was from the Ministry of Health in regard to enhancing workforce training and qualifications to ensure a more skilled caregiver workforce. Enliven recognises the need for staff training in dementia and views it as a work in progress.

“There has been a huge push in the last couple of years around increasing the confidence in training for support workers, which was led by funding through the Ministry of Health.”

Support worker training has increasingly included a unit standard at level 3 on the New Zealand Qualification Framework titled “Provide person-centred care when supporting a person with early stage dementia in a health or wellbeing setting’ and is provided through Open Doors.

“Enliven was the provider that put through the most staff...a large number of those were day programme staff, so we have worked on upskilling our workforce.”

Additionally, day programme support workers are encouraged to complete a limited credit dementia paper at level 4 on the New Zealand qualifications framework.

Research interviewees noted the importance for now and the future that support workers need to have a good grasp of dementia and implement in practice what they learnt. There is increasing emphasis on recruiting support workers with the right disposition who have empathy and understanding, a calm disposition and are focused on client needs.

In addition to appointing a clinical practice leader who has oversight at organisational level for workforce development for support workers, Enliven has also appointed dementia champions at various sites. Enliven has a lead role in educating the larger PSN organisation to enable them to become a dementia friendly organisation. Additionally, Enliven may have a role in mobilising parishes and volunteers providing them with training on dementia friendly communities.

2.4.1.4 Cultural responsiveness

Original research finding

Effective day programmes are responsive to clients and caregivers’ cultural needs and staff members are able to address issues in caring for clients in a culturally appropriate manner.

Update

Enliven is aware that they are able to strengthen their service and increase the effectiveness of their day programmes by taking into account what clients and caregivers cultural needs are. Seeking input from different ethnic groups is found to have a positive affect for clients who enjoy food, music and dancing from different cultures. Support workers are provided induction to cultural competency, which primarily involves understanding Maori and Pacific Island cultures. There has been an effort made to employ staff who have a similar cultural backgrounds as clients. Increasingly there has been a need to cater for other ethnicities in response to changing demographics of the regions such as Auckland where there is a growing Asian and Indian population. Enliven is
looking at ways to engage with these communities including connecting with providers already working there, to potentially form partnerships to best meet the needs of those communities. The research interviewees viewed developing cultural competence as an ongoing priority and challenge.

“We haven’t done a lot other than thinking around Te Whare Tapa Wha. The only other piece of work that we have done is improving our connection with...who provides a range of services for primarily Asian and Indian populations.”

2.4.1.5 Service processes

Original research finding

Effective day programmes have a focus on service processes such as targeted communication with caregivers about what happens at the day programme. The provision of adequate resources to enable transport to and from the day programme and serving of refreshments throughout the day are important aspects of the programme. This in turn enhances the ability to create a routine that strengthens a sense of security for the client. The most important advantage of adequate referral processes seem to be the efficient development of individual intervention plans with measurable outcomes and targeted support.

Update

Establishing and maintaining regular contact with caregivers is important to Enliven, however it remains an ongoing challenge to find the most effective ways of achieving it. Some methods include telephone calls, communication notebooks and invitation to special events.

Enliven continues to offer transport to and from the day programmes and refreshments during the day, both of these are key to how the programme functions. Clients get to know the drivers who are friendly to them and they grow to trust and rely on them. Having meals and snacks throughout the day helps with routine and clients within their capabilities and if they wish to participate in the preparation, delivery and clean up of these.

A note worthy innovation since the original research is at one site is a change in how they refer to clients – now called members. The shift in name is to encourage an increased sense of belonging to a club and to provide opportunities for autonomy and choice over activities.

“They’ve all got their support plans so they do activities that they choose. They have a members meeting once a month where they plan out with other members what they would like to do...there’s been a big shift towards members running their own group... those that are not able to make decisions are supported by those that can...we are there for support.”

2.5 Methods employed to measure the quality of outcomes of day programmes

Update

Enliven continues to utilise two main methods for measuring the quality of outcomes of day programmes as reported in the original research: 1) reporting and auditing processes 2) client and stakeholder satisfaction surveys.

1) Reporting and auditing processes are part of the requirements set out in the contracts with providers by local District Health Boards (DHB) that are funded by the Ministry of Health, data requirements and vary depending on the DHB. Activities include reporting on quarterly and six monthly bases and engaging in auditing processes. This subsequently
enables Enliven to use these measures to demonstrate that the needs of the clients are being met and identifies areas for improvement.

2) Day programmes are routinely surveyed using results-based accountability (RBA) surveys [15] that provide client/caregiver feedback to monitor the quality of service delivery. These measures include monitoring client outcomes and service improvement. Additionally, regular stakeholder surveys seek to gain views on what works well for the day programme and what could be improved.

The challenge in the future will be to get robust scientific evidence of improved client cognitive functioning as a result of attendance at a day programme. Currently the social and physical benefits of client functioning as a result of participating in day programmes have been documented [8]. The piloting by Enliven of cognitive stimulation therapy into its day programmes and the clinical research they commissioned along side the implementation should provide evidence of what difference the programme has made for individual clients and how implementation processes can be improved.

2.6 Future trends in dementia

Research interviewees identified a number of trends they see in delivering services to people living with dementia in the community and their caregivers. They noted statistics from New Zealand results on people living with dementia is similar to global trends. Enliven is committed to implementing client dementia pathways funded by DHBs which are designed to support people living at home as long as possible. The range of activities offered in dementia-focused day programmes has increased based on evaluation feedback and research results and in the future this is likely to be strengthened. Diagnosis of dementia especially with existing Enliven clients is likely to be a key issue re ongoing support to allow them to live longer in the community. Also noted was the continual need to strengthen staff capabilities and competencies in tailoring custom made programmes to meet the needs of those they serve. There will be a strong focus on new ways of working by assisting clients to regain function and independence to the limits of their capacity. Also noted by the research interviewees were that more work is being done around mental health in the community, hence more awareness and understanding about dementia and there is a hope that continues. There appears is less stigma about living with dementia.

Other trends identified include: noticeable increase in number of people living with dementia and in younger-onset (evidence yet to be collected whether it is a result of earlier diagnosis or increased occurrence?); dementia care will get more difficult to provide with more people being diagnosed and financial constraints placed on providers to meet the demand for community based services; lower socioeconomic group is at higher risk of not being diagnosed earlier as they do not present to their local general practitioner due to cost of visits.

Enliven in the future will continue to be concerned with psychosocial outcomes and physical support for clients and in addition it will have cognitive stimulation therapy as part of their service. Cognitive stimulation therapy – while an internationally recognised approach effective for people living dementia, however Enliven has yet to trial it. Enliven is hopeful that cognitive stimulation therapy will produce tangible success for clients in the intended pilot.

2.7 Discussion

The updated research confirmed that effective day programmes utilise the five
core elements identified in the original research with the aim to measure progress against them. These elements have been achieved in varying degrees. Client functioning has been primarily focused on improvements in the psychosocial space with intention to move towards cognitive stimulation therapy. Caregiver benefits remain an important aspect of service delivery, in particular improving on ways to ensure caregivers receive communication on how their loved one is participating in the day programmes. Workforce capability remains a work in progress for Enliven, however they have made significant progress in improving the qualifications of support workers in relation to their understanding of dementia and their role in supporting the wellbeing of clients. Cultural responsiveness is a work in progress with a strong commitment to understanding the cultural needs of clients. The primary focus is on understanding the needs of Māori as the indigenous people of Aotearoa New Zealand and Pacific Island nations living in New Zealand, additionally it was noted the need to understand how best to meet the needs of growing numbers of Asian and Indian immigrants. Key aspects of service delivery include regular and often daily interactions with clients and their caregivers. Providing transport for clients to and from the day programme and the provision of meals and a wide range of activities helps to provide a secure environment that in turn provides clients with many psychosocial benefits. Sporting and musical activities encourage movement that are designed to improve physical functions of clients. In the future cognitive stimulation therapy will be part of the day programmes.

2.8 Conclusion
An important issue globally is how to provide effective services for people living with dementia to enable them to remain at home in the community with the support of their caregivers. Day programmes have a key role to play now and in the future by providing a range of activities aimed at improving client functioning and respite for caregivers. The five core elements that demonstrate effective dementia focused day programmes have relevance to day programmes offered internationally.

Day programmes that offer a wide range of targeted activities aimed at improving client’s functioning and meet the needs of the clients’ individual plans are likely to be able to demonstrate psychosocial, physical and cognitive benefits for individuals. Clients and caregivers input into programmes is likely to result in the programme more closely meeting the needs of the client.

While in Aotearoa New Zealand has made some progress in improving the remuneration for support workers, however they remain on the lower range of pay. Internationally most support workers are also women and the issue of fair remuneration and upskilling the workforce remains an ongoing challenge.

With regards to workforce capability, findings suggest that dementia can be regarded as a specialised field of practice and that base qualifications and the goodwill and good intentions of willing individuals should be regarded as the absolute minimum workforce requirement. Upskilling the workforce by requiring them to complete qualifications related to care of people living with dementia is believed to have a positive effect on the quality of care providing they apply what they have studied.

There is growing recognition of the need to be culturally responsive to clients by recognising their diverse needs and those of the caregivers. Incorporating cultural
activities into the programme and employing staff that match the demographics of the clients are two ways of demonstrating cultural responsiveness.

Although the preference for dementia-specific programmes in the context of adult day services for older people is not clear, meeting the requirements for an effective day programmes assumes growing trends and directions for targeted interventions with specific populations, including caregivers.

Key findings on the methods employed to measure the quality of outcomes of day programmes further highlight questions about the nature and availability of evidence to inform decisions regarding the design and implementation of day programmes. Tools to document the effect of interventions are an area for continued development. A need exists to better describe and conceptualise individual and programmatic outcomes that can be implemented and measured in practice. Utilising an outcomes-based framework such as an RBA framework [14] can be a useful mechanism to for measuring the delivery of day programmes for people living with dementia and their caregivers.
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