



Evidence Briefing

**Personalised Psychosocial Supports and Care
for People with Dementia in the Community**

2018

AUTHORS

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Executive Summary

Current publicly-funded community-based dementia care in Ireland is mainly through standard homecare services, with a gap in knowledge and evidence on the value and feasibility of incorporating a more person-centred and psychosocial dimension. This evidence briefing presents the main findings from a study to bring together and build-upon the research, evaluation, and learning from the first set of projects funded under the HSE & Genio Dementia Programme. It combines results from direct research on the projects with evidence from a review of the wider international literature, and provides new knowledge and evidence on the impacts and value for money of personalised supports in dementia care in Ireland.

The study focused especially on two substantial dementia programme demonstration projects, one in South Dublin and the other in South Tipperary. Together these supported more than 300 people with dementia and their carers through a range of innovative personalised and psychosocial interventions. The projects had a core focus on supporting people with dementia and their carers/families to 'live well with dementia', with an emphasis on personhood and provision of support in a personalised manner. Although innovative in the Irish context, the broad mix of supports provided by the projects encompassed recognised areas of intervention in dementia practice and research. These include psychosocial and psycho-educational interventions, personalised homecare and respite, and recreational therapy and reablement approaches.

Both projects allocated substantial resources to personalised home supports, aiming to simultaneously provide respite for carers and positive, person-centred benefits for people with dementia. They also provided supports to connect (or re-connect) persons with dementia with activities in the community, and a variety of other social and therapeutic supports. Participants covered a broad spectrum in severity of dementia and associated capacities, interests and needs, and included a substantial number with a high risk of entry to long-stay residential care in the near-term. Combinations of supports used and levels and patterns of usage varied widely, depending on participant circumstances and needs.

Substantial wellbeing gains

Direct quantitative and qualitative evidence from the projects shows how the programmes of personalised supports provided substantial wellbeing gains for many people with dementia. They facilitated living well or at least a lot better with dementia, and provided benefits for the person with dementia, for family carers, and at the family level.

Some key areas of benefit for persons with dementia and their carers	
Person with Dementia	<ul style="list-style-type: none">▪ enhanced personhood▪ gains in subjective wellbeing▪ enabled to live longer at home
Family Carers	<ul style="list-style-type: none">▪ reduced burden and negative impacts on wellbeing▪ enhancement of more rewarding aspects of caring▪ reduction in opportunity costs of caring
Couples/Families	<ul style="list-style-type: none">▪ relationship-related gains▪ satisfaction from sustaining living at home

Each form of support proved useful for many people who used it. In addition, many people used a number of the supports on offer and gained substantial value from the possibility to select and tailor support packages that met their preferences, circumstances, and needs. These direct results from the projects are congruent with the evidence from the wider research literature indicating the value of multi-component programmes, the importance of tailoring interventions to relevant and achievable domains of gain, and the particular value from interventions that target gain for both the person with dementia and family carer.

Especially compelling are the unprompted testimonials from dementia programme service users. These bring to life the real-world meaning and value of the interventions in the lives of people with dementia and their family carers. They show the enormous value and impact of psychosocial services in social care for people with dementia living in the community.

Value for money

Detailed data on support hours provided to each person enabled analysis of the economics and value for money of the programmes of personalised supports. Overall, the levels of support utilised by participants in the projects averaged around one to two hours per week, but with flexible access and wide variation across individuals in the mix of supports and total number of hours of support used. From a national resource allocation perspective, a relatively small percentage increment in the standard allocation of social care supports for dementia care could enable provision of additional personalised psychosocial supports for a large number of people with dementia.

A separate economic analysis of project costs conducted by other researchers focused on people with dementia identified as having high risk of admission to residential care in the near-term. It concluded that the projects potentially helped avoid/delay entry to long-stay residential care for many of these individuals, with an associated potential for significant cost savings. The evidence of demonstrable quality of life and subjective wellbeing gains found in our research provides a substantial and crucial addition to the value and value-for-money case. In their own right, these gains for persons with dementia and family carers represent considerable value for the dementia care system, even before taking into account the potential long-stay residential care cost savings.

Conclusions

There is a demonstrated and compelling value case for provision of personalised psychosocial supports as part of care for people with dementia living in the community in Ireland. This is underpinned by an extensive range of evidence from the projects and from the wider research literature. The incremental costs, over and above standard care costs, are relatively small and represent good value for money in delivering on dementia policy and the National Dementia Strategy. In addition, there is the potential for substantial savings from delay or avoidance of long-stay residential care costs.

The evidence presented in this report indicates a strong case for resourcing the provision of personalised psychosocial supports across the trajectory of dementia, including the personalised supports of lower intensity demonstrated by these projects. These lower intensity supports could reach large numbers of people with dementia and family carers, particularly at an earlier stage, and could then be scaled and reconfigured to respond as individual need increases. The projects show that it is practically feasible to implement these types of services at local level within HSE community care services. The basic model could be replicated in every area across the country, whilst allowing for tailoring and fine-tuning to local needs and capacities.

1 Introduction

Current publicly-funded community-based dementia care in Ireland is mainly through standard homecare services, with a gap in knowledge and evidence on the value and feasibility of incorporating a more person-centred and psychosocial dimension. This evidence briefing presents the main findings from a study to bring together and build-upon the research, evaluation, and learning from the first set of projects funded under the HSE & Genio Dementia Programme.

The study focused especially on two substantial dementia programme demonstration projects, one in South Dublin and the other in South Tipperary. Together these supported more than 300 persons with dementia and their carers through a variety of innovative personalised and psychosocial interventions. Each project operated through a consortium comprising staff from HSE services and a range of third sector and community organisations operating within the catchment area. HSE Services for Older People led the *Living Well with Dementia* project in the Stillorgan/Blackrock area of South Dublin and HSE Old Age Psychiatry services led the *5 Steps to Living Well with Dementia* project in the South Tipperary area.

Approach and methods

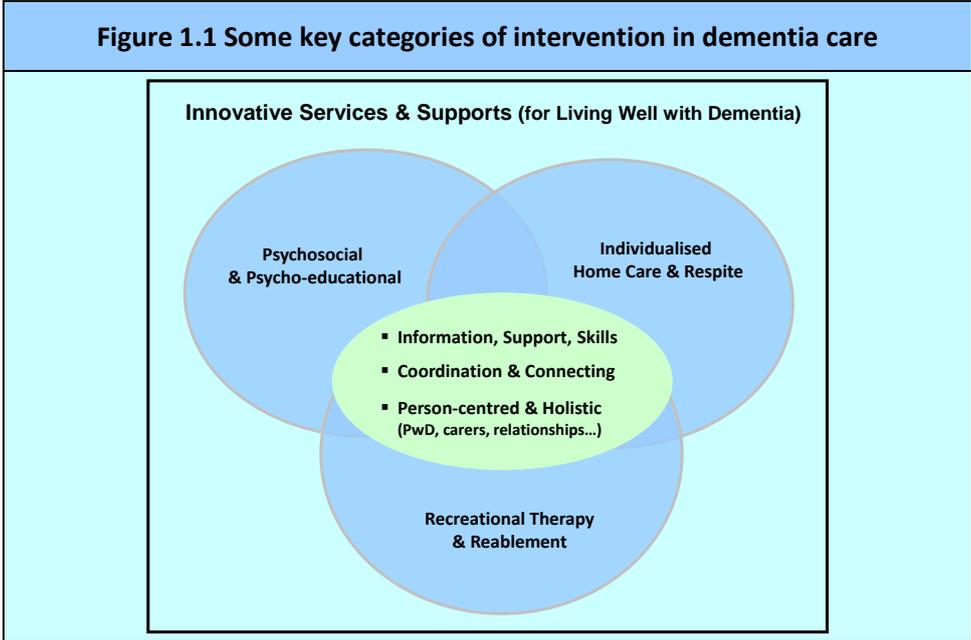
The research methodology included substantial secondary analysis of available data from the projects and an international evidence review. The secondary analysis included quantitative data on support usage from the dementia programme database, results from evaluation studies conducted on aspects of the programmes (e.g. respite, assistive technology and telecare), and a large body of qualitative feedback and testimonials from people with dementia and family carers using the services. Collectively, these analyses and literature review provide a powerful triangulation of evidence on the ways that the innovative services and supports may facilitate living well with dementia for many, and on the value case for dementia care services from provision of these services.

A spectrum of psychosocial supports

Box 1.1 presents the broad range of psychosocial and personalised care supports offered by the projects.

Box 1.1 Overview of supports provided by the projects
<ul style="list-style-type: none">• Befriending (including activity support, driving, etc.)• Community connecting, supported by dementia support workers• Social supports (exercise group, bridge, Musical Memories choir, creative writing group, art appreciation) and social events (Christmas parties, tea dances, etc.)• Therapies (cognitive stimulation therapy, art therapy, music therapy)• Family carers information and family networking events; family carers training• Assistive technology & telecare; Memory Technology Library• Home-based supports & Respite• Community awareness activities

Looking at the wider research and practice evidence, these personalised supports map to key categories of intervention in dementia care, including psychosocial, psycho-educational, recreational therapy and reablement, homecare, and respite (Figure 1.1).



2 Outcomes and benefits – the evidence

The two projects provide a broad canvas of experience of persons with dementia and family carers utilising different mixes of services and supports. Each service and support has its own characteristics, and these influence which domains of wellbeing they are likely to impact. Given that many people used more than one support, the analysis applies both service-specific and cross-cutting perspectives. This enables examination of the contribution made by each service in its own right as well as the collective impact for each person from the combined mix of services they used.

2.1 Overview of the international research evidence

In this analysis, evidence from the research literature is primarily taken from systematic reviews. These are considered a gold-standard source of evidence, synthesising the results from an entire body of research, and taking into account quality and robustness of the research in reaching conclusions on the evidence and its soundness. Box 2.2 presents an overview of this wider research, highlighting the growing body of evidence indicating positive impacts for the range of interventions implemented in the dementia programme projects.

Like many areas of social care, there has been less research on cost-effectiveness and very little in the Irish context, and the wider health economics field provides only limited health-related quality of life evidence to guide resource allocation decisions in dementia care (Banergee et al, 2009). Nevertheless, there is an emerging body of research pointing to cost-effectiveness of the types of supports offered by the dementia programme projects. A broad review of cost-effectiveness studies, covering both pharmacological and non-pharmacological interventions, found positive evidence of varying strength across a range of outcome domains (Knapp et al, 2012). Other systematic reviews have found evidence of cost-effectiveness for group-based music therapy (Livingston et al, 2014). Value for money analyses also suggest a very positive return on investment from peer support

groups for people with dementia and family carers incorporating trained facilitation and activities such as music, games, reminiscence, and exercise (Willis et al, 2016).

Box 2.2 Overview of evidence from the wider research literature		
Type of support	Evidence reviews	Main findings
Personalised home support & respite	<i>Arksey et al (2004); Knapp et al (2012); Mason et al (2007); Shaw et al (2009); Van't Leven et al (2013)</i>	<ul style="list-style-type: none"> • Tailoring / individualising works best • Carers benefit most when care recipient is seen to benefit (dyadic approaches) • Can be cost-effective
Information & skills (psycho-education)	<i>Pusey and Richards (2001); Selwood et al (2007); Livingston et al (2005); Parker et al (2006)</i>	<ul style="list-style-type: none"> • Improved carer psychological wellbeing • Better managing of neuropsychiatric symptoms and challenging behaviours • Focused skills development & psycho-education have best results
Music & singing	<i>Ueda et al (2013); McDermott et al (2013); Hulme et al (2010); Livingston et al (2014); Victor et al (2016); Vasionyte and Madison (2013)</i>	<ul style="list-style-type: none"> • Short-term improvement in mood; cognitive and physiological impacts • Reduction in behavioural disturbance • Evidence of cost-effectiveness, especially music (therapy) to meet needs of person with dementia and carer • Also, broader social / participative value
Befriending	<i>Windle et al (2011); Lawlor et al (2014)</i>	<ul style="list-style-type: none"> • Reductions in loneliness • Positive impacts on mood • Also, broader social / participative value
Exercise classes	<i>Forbes et al (2013); Farina et al (2013); Heyn et al (2004); Van Uffelen et al (2008); Potter et al (2011); Hulme et al (2010)</i>	<ul style="list-style-type: none"> • Improved physical functioning • Possible cognitive improvements • Also, broader social / participative value
Telecare & Assistive Technology	<i>Davies et al (2013); Poole (2006); Topo (2009); NICE (2015); Cullen et al (2015)</i>	<ul style="list-style-type: none"> • Logistical supports for carers (e.g. reassurance; alerting when needed; better sleep; more independence for PwD) • Enabling PwD (e.g. through time orientation)
Arts / creative	<i>Young et al (2015)</i>	<ul style="list-style-type: none"> • Cognitive impacts: attention, memory • Enhanced communication and engagement

2.2 Evidence from the dementia programme projects

2.2.1 Personalised home support & respite

The research literature provides a range of evidence on the contribution of home support and respite services for carers and care recipients (Arksey et al, 2004; Knapp et al, 2012; Mason et al, 2007; Shaw et al, 2009; Van't Leven et al, 2013). Overall, the research indicates that respite care can be cost-effective, but tailoring or individualising of respite is important for optimal benefits. Carers seem to benefit most if the 'respite' takes account of both the carer's and care recipient's needs, and where they see the care recipient to be benefiting. Dyadic approaches focusing on the needs of both parties may be particularly effective.

Both Irish dementia programme projects provided personalised home-based supports as an important component of their programmes. These were additional to, and different from, any standard homecare supports that people with dementia might use. A key difference was the focus on providing direct wellbeing gains for the person with dementia at the same time as providing respite for the family carer. The evidence from the projects is strongly consistent with that from the wider research literature. External evaluations (Cahill et al, 2014; 2014a), and testimonials from people with dementia and family carers, illustrate how personalised home supports benefited persons with dementia and carers (Box 2.3).

Box 2.3 Testimonials – Dual benefits (for person with dementia and family carers)

"I receive 6 hrs service each week, this gives me time to do my shopping and any other business I have to do. I know I can rely on the girls [Dementia Support Workers] to look after my mother's needs as they always bring a smile to her face. They keep her active by doing activities with her or even taking her for a walk. These things I don't seem to get time to do with my mother." (Family carer)

"External stimulation and activation with the person outside the family home is very beneficial... By chatting about greyhounds and all topics he would have been interested in. By [dementia support worker] being here she gives me a break as I have to be up several times during the night. Helps us to cope. As for my husband ... the fact of [dementia support worker] helping him reading, etc. has a calming effect for several days." (Family carer)

"This service is of huge support to us as a family...mam's support worker is so good to my mam and mam is very secure with her. It is fantastic for mam's confidence too and gives us, the family, vital respite if only for a few hours every week, which we really appreciate." (Family carer)

"[Carer] came 3 times a day for 5 days a week, a total of 15 hours. This made a huge difference to both our lives ... My husband enjoyed the visits from the carers. It added variety to his routine and it gave me freedom to do housework, go shopping or meet friends." (Family carer)

"The service is excellent; it works for both the person with dementia and the carer. Having someone to come to your home and give you a break, and know they can care equally as well as you, is great." (Family carer)

2.2.2 Information and skills

The research literature provides a range of evidence on the contribution of information, skills development and psycho-education programmes for carers of persons with dementia (Pusey and Richards, 2001; Selwood et al, 2007; Livingston et al, 2005; Parker et al, 2006). Positive impacts identified include improved carer psychological wellbeing and better management of neuropsychiatric symptoms and challenging behaviours. Focused skills development and psycho-education appear to have the best results. NICE guidelines in England recommend psycho-education as a support for family carers.

Both dementia programme projects included provision of information about dementia supports as part of their service. Testimonials from family carers from the Stillorgan/Blackrock project show the experienced value of these supports for many carers and people with dementia (Box 2.4).

Box 2.4 Testimonials - Information and Skills

"I found the talks and discussions at [location] very beneficial in understanding dementia and ways and methods to help in supporting people with dementia stay at home and to be cared for in their own homes, and in particular the services and supports that were available locally in supporting carers and their families ..." (Family carer)

"Learned so much throughout this six week intensive training course. We also shared our own personal experience ... Great support for one another ... It taught my family and myself the right approach, understanding and educated us about the best way to care for and do our best for our family member. It also highlighted what we were doing both right and wrong! By educating us about dementia we became more understanding and better carers so it was a win win situation. We became much happier and more confident carers, which had a knock on effect naturally so our loved one with dementia became happier and more assured that the right care and understanding was at hand! ... A big plus was learning about the advanced stages of dementia so we were well equipped for each stage of dementia as it arrived!" (Family carer)

2.2.3 Choir

The research literature provides a range of evidence indicating benefits for people with dementia from music therapy, singing, and participating in a choir. These include short-term improvement in mood, cognitive and physiological impacts, and reduction in behavioural disturbance (Ueda et al, 2013; McDermott et al, 2013; Hulme et al, 2010; Livingston et al, 2014; Victor et al, 2016; Vasionytė and Madison, 2013). Evidence also indicates cost-effectiveness from the social care perspective, and supports the case for delivery of such interventions by health and social care services, particularly the provision of group music therapy that meets the needs of both the person with dementia and their carer. In addition, there are benefits from the more general social and participative nature of choir sessions. The Stillorgan/Blackrock project organised the Musical Memories Choir as an initiative to give people with dementia and family carers an opportunity to come together in a relaxed environment and reconnect through music. Testimonials from people with dementia and family carers show the experienced value of participation for many of those who attended, and often for carers and the wider family as well (Box 2.5).

Box 2.5 Testimonials - Musical Memories Choir

"I enjoy the music and wouldn't miss it for anything. I couldn't go for a while because [carer] was away but looking forward to going back. I like the music and especially the old songs. I used to sing a lot." (Person with dementia)

"... [husband] just loved the music; he just took off, no inhibitions whatsoever. He was always happy. The support and friendship is marvellous..." (Family carer)

"Choir is invaluable. Mum has said "I'm really enjoying this". She likes the room, it's so uplifting and she remembers being there week on week. The musicians are marvellous and add extra dimension ... It's important to keep it going. If there's anything I can do to help, I'd be more than happy to help." (Family carer)

"We are delighted with it and [wife] looks forward to going each week. I don't take her; my son does and says she likes it. She comes home in a good mood." (Family carer)

"Absolutely love it. We haven't missed a Saturday since it started. It's a lovely group of people ... [they] are all great." (Family carer)

2.2.4 Befriending and Community Connecting

The research literature does not provide much evidence on one-to-one befriending for persons with dementia, per se. However, a body of evidence is available on the benefits of befriending for older persons more generally. This includes evidence from an Irish randomised controlled trial (RCT) showing a reduction in loneliness (Lawlor et al, 2014), and wider international evidence yielding similar conclusions (Windle et al, 2011).

The Stillorgan/Blackrock project provided individual friendship volunteers, carefully selected by a volunteer coordinator, to support people with dementia to pursue their interests and participate in their local community. The South Tipperary project provided a 'community connecting' support, delivered by a dedicated community connector function as well as through one-to-one support from Dementia Support Workers for participation in activities. Testimonials from family carers in the projects show how valuable this can be for some people with dementia (Box 2.6).

Box 2.6 Testimonials - Befriending

"For me the most helpful support has been my two wonderful men, [volunteers] who faithfully come to take [husband] out every week. It is the only male company he has and is very important to us ..." (Family carer)

"... my husband has a befriender who is a gem, one in a million...in the short time [my husband] and I have been involved with the project it has had an enormous impact on our life. [He] now has a focus to his week ... looks forward eagerly to be with his 'friend' on a Wednesday. This is a very special day in the week, he gets up in the morning wondering what they will do and always comes home full of the joys of spring and stimulated - he sits down, writes it up in his journal. It also gives me a break to do some necessary catch up or just meet a friend and have a coffee ..." (Family carer)

"Volunteer programme has been a great benefit to [husband]. He really looks forward to [volunteer's] visit each week. This is something [he] feels he is doing alone ..." (Family carer)

2.2.5 Exercise classes

The research literature provides a range of evidence indicating potential benefits from exercise programmes for people with dementia (Forbes et al, 2013; Farina et al, 2013; Heyn et al, 2004; Van Uffelen et al, 2008; Potter et al, 2011; Hulme et al, 2010). This includes improved physical functioning and some evidence suggesting possible cognitive improvements. The Stillorgan/Blackrock project ran a weekly exercise programme that welcomed people with dementia. Testimonials from family carers from the project show how valuable this can be for people with dementia and carers (Box 2.7).

2.2.6 Telecare and assistive technology

'Telecare' refers to systems that alert carers when the person with dementia has a need or is at risk; 'assistive technology' refers to stand-alone equipment for use by the person with dementia. The research literature provides a range of evidence on the contribution of telecare for carers, including reviews (Davies et al, 2013; Poole, 2006; NICE, 2015; Cullen et al, 2015) and individual evaluation studies (e.g. Woolham, 2005). There have also been a number of Irish studies (Keogh, 2010; Graham et al, 2011; Cullen et al, 2016).

Box 2.7 Testimonials - Exercise classes

"The exercise group is a great way for [him] to be active; to socialise...and provided a structure to his week, that also includes the Musical memories Choir; it gives him a purpose and something to look forward to, it gives him an outing and a way to interact with other people and to feel he belongs to something and to feel valued". (Family carer)

"... my mother looks forward to her weekly visit to bridge and exercise groups. The afternoon suits her body clock, she can genuinely participate in the card games and exercises and the coordinators are so kind to her ..." (Family carer)

"The Tuesday exercise class gave my husband great pleasure and we both enjoyed the friendship and the cup of tea after the class. My husband enjoyed the class and it was lovely to see the smile on his face as he did the exercises. It was great to have something to do, he looked forward to the class and meeting everyone. The project took away the isolation of feeling so alone in dealing with the dementia. My husband died in April and I am so glad we were able to take part and I shall treasure the memories ..." (Family carer)

"... the exercise group is the one we avail of at present; having been involved in sport all his life [husband] enjoys it very much ..." (Family carer)

Systematic reviews have found some evidence for impacts on carer stress and strain, and individual evaluation studies have shown the usefulness for carers of the practical and logistical support provided by telecare. The wider research literature also provides some evidence on benefits of assistive technology for people with dementia, for example, through helping time orientation and prompting or guiding activity and memory, although likelihood of benefit appears to be very individualised (Topo, 2009; Cahill et al, 2007; Carswell et al, 2009).

Both projects included telecare and assistive technology within their portfolios of supports, and external researchers evaluated this component of the dementia programme (Cullen et al, 2016). All 24 telecare users in the study reported positive benefits, often major benefits; and most of the 20 users of assistive technology in the study rated it very useful (62.9%) or somewhat useful (20%), although one-in-six (17.1%) rated it not useful. Box 2.8 presents some testimonials from users of telecare and assistive technology.

Box 2.8 Testimonials - Benefits from telecare & assistive technology

"This gives her independence. You can monitor but she still feels she is doing her own thing ... I can watch what she's doing and not go near her unless I have to. Otherwise I'd have to be going in and out of the room all the time and that would drive her cuckoo altogether." (Family carer)

"It is peace of mind to know that if she does go wandering ... we will get an alert." (Family carer)

"She'd have a risk of falling ... she can forget to use the frame ... if I'm in the kitchen doing something or in the bedroom or anywhere around the house ... I can go outside to hang up my clothes now, without having the worry of it because I know it's going to beep. I can go out, my garden is out there, my flowers, and I can go out to that, and I can go out with peace."

"I'd be in a bad way without it. I may think it was Monday, instead of Saturday, and that's a regular occurrence. It would be a nuisance if I didn't have the clock. Otherwise I'd turn on the radio - but it might or might not give you the information." (Person with dementia)

"Stopped all the questions - I didn't have to keep saying over and over what day it was. It was nice not to be asked. She used to knock on my bedroom door at night but this stopped once [the] clock was in place." (Family carer)

2.2.7 Arts / creative activities

The evidence from the research literature suggests that arts-based activities can have a positive impact on cognitive processes, in particular on attention and stimulation of memories, as well as enhanced communication and engagement with creative activities (Young et al, 2015). A small number of people with dementia from the projects availed of arts-related activities, including creative writing, art appreciation, and art therapy. Testimonials from participants suggest that participants often benefited substantially (Box 2.9).

Box 2.9 Testimonials – Arts/Creative activities

"... It helped to re-awaken memories in the group, of people and places forgotten, which was wonderful and very re-assuring, very interesting ..." (Family carer)

"The friendship developed from it and the nice people I met. It stimulated my mind". (Person with dementia)

"Enjoyed putting into words my thoughts and happy memories. Putting a story together and reading it back to the group ..." (Person with dementia)

"[He] does not recall the workshops; however it was definitely stimulating and provided lots of ideas to continue". (Family carer)

"I find it challenging to get him to go to anything with the word 'Dementia' or 'Alzheimer's' in it. But by plodding on and constantly reminding him or bringing him with me to different groups, he enjoys them when he gets there. The difference with this writing group is that he has gone on his own and has no problem doing so, other than being late". (Family carer)

"... From me and [my husband] - who was totally 'clued in' to the experience. That gave me great pleasure". (Family carer)

"He does not speak much at home so it's great to see that he did so in this group". (Family carer)

"I enjoyed this group immensely, especially the camaraderie". (Person with dementia)

2.2.8 Benefits from a combination of supports

The wider research literature provides evidence of the value of multi-component approaches (e.g. Cooke et al, 2001; Smits et al, 2017). A broad systematic review of interventions for carers of people with dementia used meta-analysis to integrate the results of 127 studies (Pinquart and Sörensen, 2006). It found that a range of interventions tended to have significant but small effects on burden, depression, subjective well-being, carer ability/knowledge, and symptoms of care recipients. Only multi-component interventions reduced the risk for institutionalization.

Another extensive review covered a range of interventions to assist caregivers to support people with dementia living in the community (Parker et al, 2006). They found evidence to support the use of well-designed psycho-educational or multi-component interventions. The direct feedback from project participants shows how a combination of supports was beneficial for many (Box 2.10).

Box 2.10 Testimonials – Benefits of using a variety of services and supports

"Volunteer programme has been a great benefit to [husband]. He really looks forward to [volunteer's] visit each week. This is something [husband] feels he is doing alone. The exercise class again [name] enjoys as it is something he attends alone ... Community awareness in [local] shopping centre is excellent. When I booked an eye test I was given extra time and the staff were very understanding ... Living Well have supplied a tracker for [husband] which has given all the family great comfort knowing that if he did get lost we would be able to find him as soon as he was missed ... Living Well have provided me with two mornings per week for [husband] which has allowed me to continue working outside the home. This has helped in making life as normal for all the family as possible. Social events allow both carer and client to meet people in a similar situation and be relaxed". (Family Carer)

"I found the family carers' information nights very helpful ... It has made a big difference in that one doesn't feel one is battling this awful disease alone. There is always help and support from 'Living Well with Dementia' at the end of the phone, and people will listen to you and it's very obvious that everybody involved really cares about the dementia patient ... My husband and myself have been attending the Musical Memories Choir since it started two years ago and it is so much part of our Saturday now and we really look forward to it, as the weekend can be difficult enough ..." (Family Carer)

"[Family Carers Information and family networking events]: The information was very relevant ... At the time I was finding various aspects of my wife's illness very challenging, e.g. trying to encourage her to eat, and I found the presentation very timely and very relevant. The project team members were genuinely interested in helping me and I sensed their caring and compassionate qualities. It was a relief to meet people who were experiencing the same challenges as a carer. Social events, simply to relax with the project team and other carers ... Respite, once off, great help ... help to deal with pressures that otherwise I would not have been able to cope with ... As a result of the education I received, I was better prepared for the day to day challenges of my life as a carer, and therefore my wife received more consistent care. The carers gave me valuable support and breathing space. The respite reduced the pressure I was living with". (Family Carer)

2.2.9 Some key areas of benefit

The evidence presented above demonstrates the strong positive contribution of each form of support for many people with dementia and carers who availed of it. This provides useful insight into the multiple dimensions of wellbeing and wellbeing gain in dementia, an area where research and knowledge are still quite limited.

The possibility to avail of the most appropriate support, at the right time, was an important feature of the dementia programme. This requires the availability of a portfolio of supports to select from, as well as flexibility in their provision to enable an individualised and person-centred approach. The demonstration project funding allowed the HSE services and their partners in the local consortia to do this, without the constraints of the more standardised and less personalised approach that generally characterises usual care in dementia services in Ireland.

Box 2.11 presents a framework identifying some key areas of benefit for persons with dementia and family carers, as well as the combined benefits for both parties through gains linked to familial relationships. This provides an organising framework for extracting and presenting a more global and cross-cutting perspective on benefits achieved, to complement the more differentiated analysis by specific support type presented earlier.

Box 2.11 Some key areas of benefit for persons with dementia and their carers	
Person with Dementia	<ul style="list-style-type: none"> ▪ enhanced personhood ▪ gains in subjective wellbeing ▪ enabled to live longer at home
Family Carers	<ul style="list-style-type: none"> ▪ reduced burden and negative impacts on wellbeing ▪ enhancement of more rewarding aspects of caring ▪ reduction in opportunity costs of caring
Couples/Families	<ul style="list-style-type: none"> ▪ relationship-related gains ▪ satisfaction from sustaining living at home

Benefits for People with Dementia

Various characteristics of dementia make it challenging to assess the impacts of interventions for people with dementia. Cognitive changes often limit the extent to which people with dementia can provide direct appraisals, so evidence is often based on observation or proxy reports by family carers or others. Development of measures that better capture quality of life has been an area of focus; the DEMQOL instrument, for example, captures feelings, memory, and everyday activity and experiences (Smith et al, 2007). From the perspective of living well with dementia, research and service developments have focused on enhancement of personhood and subjective wellbeing (happiness/pleasure or so-called 'hedonic' benefit) as two important outcome domains for people with dementia. Many of the testimonials from people with dementia and carers presented earlier show these types of gains for people with dementia using particular supports. This section collates some of these, as well as some additional testimonials, to illustrate personhood and subjective wellbeing gains provided by the project supports.

Personhood

Kitwood's work is especially associated with the view that dementia care, and social perspectives on dementia more generally, should focus on enhancing the personhood of people with dementia (Kitwood, 1997). Promoting personhood and provision of person-centred care are given a central place in the Irish National Dementia Strategy (Department of Health, 2014). Types of support that may particularly contribute to personhood include care that combines personalised supports, provision of reablement and recreational inputs, and various social activities. These include one-on-one and group activities, and may be for the person with dementia only, or for both person with dementia and family carer. A number of testimonials from people with dementia and family carers provide vivid illustration of personhood gain through the projects' supports (Box 2.12).

Subjective wellbeing

Subjective wellbeing perspectives focus on positive wellbeing of people, as measured by life satisfaction, happiness, and other such indicators. The testimonials show the happiness and pleasure provided to many people with dementia from the project supports and participation in activities (Box 2.13).

Box 2.12 Testimonials - Personhood gain

"You open a box that has been closed for 50 years and all the memories come out ..."
(Person with dementia - engaging in creative arts)

"Mum was stimulated in a way different to home/family stimulation. That made her come alive again as she used to be. For all the time that Mum has lost to us, these occasions gave us precious moments when we got her back and she found herself again ..." (Family carer)

"Without the project, [brother] would definitely have been in a nursing home by now, or even died. Instead, he's living a supported, independent life that's full of meaning. We can support him too because we're not alone ... [brother] "a different person" ... You almost wouldn't recognise him. At the Christmas party, he was up singing and dancing. I couldn't believe it." (Family carer)

"Volunteer programme has been a great benefit to [husband]. He really looks forward to [volunteer's] visit each week. This is something [husband] feels he is doing alone. The exercise class again [husband] enjoys as it is something he attends alone ..." (Family carer)

"The project has vastly improved [husband's] quality of life; it has helped restore his confidence within himself and given him a feeling of self-worth". (Family carer)

"Enjoyed putting into words my thoughts and happy memories. Putting a story together and reading it back to the group ..." (Person with dementia)

Box 2.13 Testimonials - Subjective wellbeing (happiness and pleasure)

"I know I can rely on the girls to look after my mother's needs as they always bring a smile to her face. They keep her active by doing activities with her or even taking her for a walk. These things I don't seem to get time to do with my mother." (Family carer)

"He looks forward eagerly with his 'friend' on a Wednesday. This is a very special day in the week; he gets up in the morning wondering what they will do and always comes home full of the joys of spring and stimulated". (Family carer)

"We enjoyed the social events so much, Tea dances, parties etc. Also, support on hand for carers at the exercises ... [Husband] just loved the music; he just took off, no inhibitions whatsoever. He was always happy. The support and friendship is marvellous". (Family carer)

"I don't always go with her as you know – the rest of the family take her sometimes but we all agree that she (mother) loves it. She is comfortable and feels great ownership of the choir. She comes out feeling great ..." (Family carer)

Aspects of this may include enjoyment in the moment, general and sustained mood uplift, and having something to look forward to. Frequency and continuity of access to the support or activity will influence this. Cognitive capacity and memory will also affect the potential for these types of gain; for example, some people may have no memory of an activity even if they got great pleasure in the moment. In such cases, they are unlikely to derive benefits from looking forward to the next session, although they may maintain more generalised mood benefits in the period between sessions. All forms of benefit are of value, even when fleeting and in-the-moment.

Benefits for Family Carers

Family carers of people with dementia may benefit in a variety of ways from supports provided by dementia care services. The wider research literature suggests that reduced burden and mitigation of negative wellbeing impacts, and reduction in opportunity costs of caring, can especially contribute to better quality of life for carers (Farina et al, 2017). Family carer testimonials show how the project supports provided substantial benefits in these areas for many family carers (Box 2.14). The supports could help them to better manage the care process, reduce some of the burden and strain, enable them to have some life of their own, and provide opportunities for enjoyment and pleasure. Carers also reported benefits from not feeling alone and from having some sense of hope and reassurance

Box 2.14 Testimonials - Reduction of burden & opportunity costs
<p><i>"Took off some pressure - got out extra day per week - felt happier - a sense of good wellbeing for the person."</i> (Family carer)</p>
<p><i>"I get to visit my friends and family on Monday...a great help to me and my sanity"</i> (Family carer)</p>
<p><i>"It has given me time for myself to be able to go out for the time that the person is there, knowing my Mum is safe."</i> (Family carer)</p>
<p><i>"The service is excellent, it works for both the person with dementia and the carer. Having someone to come to your home and give you a break and know they can care equally as well as you is great."</i> (Family carer)</p>
<p><i>"Because really, before this, the way I was feeling was "I can't do this". So this (monitor) has helped the whole situation, you know. It works both ways. If I hadn't been able to look after him he wouldn't be able to be there you know ... I was stressed out at night running up and down...this has been my saviour you know. It's very good."</i> (Family carer)</p>
<p><i>"[Made] a big difference. We no longer felt we were alone and the source of information was very reassuring ..."</i> (Family carer)</p>

Relationship and wider family benefits

The testimonials show that the project supports often provided benefits for both the person with dementia and family carer, as a couple, and sometimes for the wider family as well. These relationship gains may often be as important and valued as individual benefits for any one of the parties (Box 2.15).

Box 2.15 Testimonials - Relationships / benefits for all parties

"Joining the musical memories choir has brought us both joy and the social aspect is very important and of course the tea dance, lovely and still able to tread a measure especially the Waltz ... It has broadened our horizons ..." (Family carer)

"We both went to some of the social events and really enjoyed the interaction and the dancing ..." (Family carer)

"The project managers helped us to get things in perspective and consequently my relationship with [wife] has improved and there is a lot less conflict now and I've learned to steer clear of trigger points for conflict ..." (Family carer)

"We love the art appreciation ... attended every session and look forward to many more. It really brings out a spark in [husband]. We also love the tea dances ..." (Family carer)

In addition to the direct forms of wellbeing gain described above, the evidence also shows the more global benefits for families deriving from the person with dementia remaining living at home, and from the family carers' ability to maintain this. A number of the family testimonials underlined this aspect (Box 2.16).

Box 2.16 Testimonials - Satisfaction from person with dementia living at home

"It has helped to keep Dad at home as we do not wish to put him into care. It has also taken pressure off the family as we all get a night off each week." (Family carer)

"It has been essential to my being able to keep [husband] at home, was considering a Nursing home before this began. Keeping [him] at home has been so important for both him and me." (Family carer)

"... [husband] has Alzheimer's for about seven years and for the past two years I could not have coped without the Musical Memories Choir, the social events - Christmas parties, Tea Dances and various other activities ..." (Family carer)

"Information and support ... ; exercise class and choir were also invaluable both for [husband] and me ... Looking after someone at home without all of the above supports would, in my view, be impossible ... Keeping patients out of nursing homes and hospital must save money and provide appropriate care". (Family Carer)

"... if she had not had the happy experience of linking up with the LWwD groups it is hard to see if she could have continued living independently ... I received a lot of support because at times I felt overwhelmed by the responsibility and stress ... I have no doubt [wife] would be in a home now without their support ..." (Family Carer)

Notwithstanding the positive results, it must be acknowledged that dementia is a degenerative disease with increasing care and support needs as the condition progresses. It is unlikely that any support system can solve all the problems and challenges of caring for persons with dementia. Although family carers reported enormous value and benefit from the supports provided by the projects, they still provided a large number of caring hours (O'Shea and Monaghan, 2016). Interviews with a sample of people using the supports in each project - mainly the group at high risk of moving to long-stay residential care - found that many carers experienced a substantial ongoing

burden from caring. This was particularly where there were other demands on carers such as work, family commitments, their own ill-health, or where the person with dementia exhibited responsive behaviours that were challenging for carers.

Despite these challenges in caring, other data from the interviews suggests that carers' health and wellbeing generally remained fairly constant over the time period between interviews. The project supports may have helped many family carers to continue caring for longer without major negative consequences for their health and wellbeing. If not overburdened and overwhelmed by the challenges, family carers can gain many positives from supporting the person with dementia to live as well as possible.

3 Resource allocation and value case

3.1 Amount and type of support usage

Persons with dementia became participants in the projects on a rolling basis over the course of the programmes. They varied in the duration of their involvement and in the intensity of their support over the period they were with the project (Table 3.1).

Table 3.1: Time on project and personalised support usage

		Stillorgan/ Blackrock	South Tipperary
Weeks on project (median)	Registered with project	82	101
	'Active' period of usage	53	18
Total hours used		18,314	11,235
Number of persons		95	201
Intensity of support usage in hours per person/week (median)	Registered with project	1.0	0.5
	'Active' period of usage	1.7	2.0

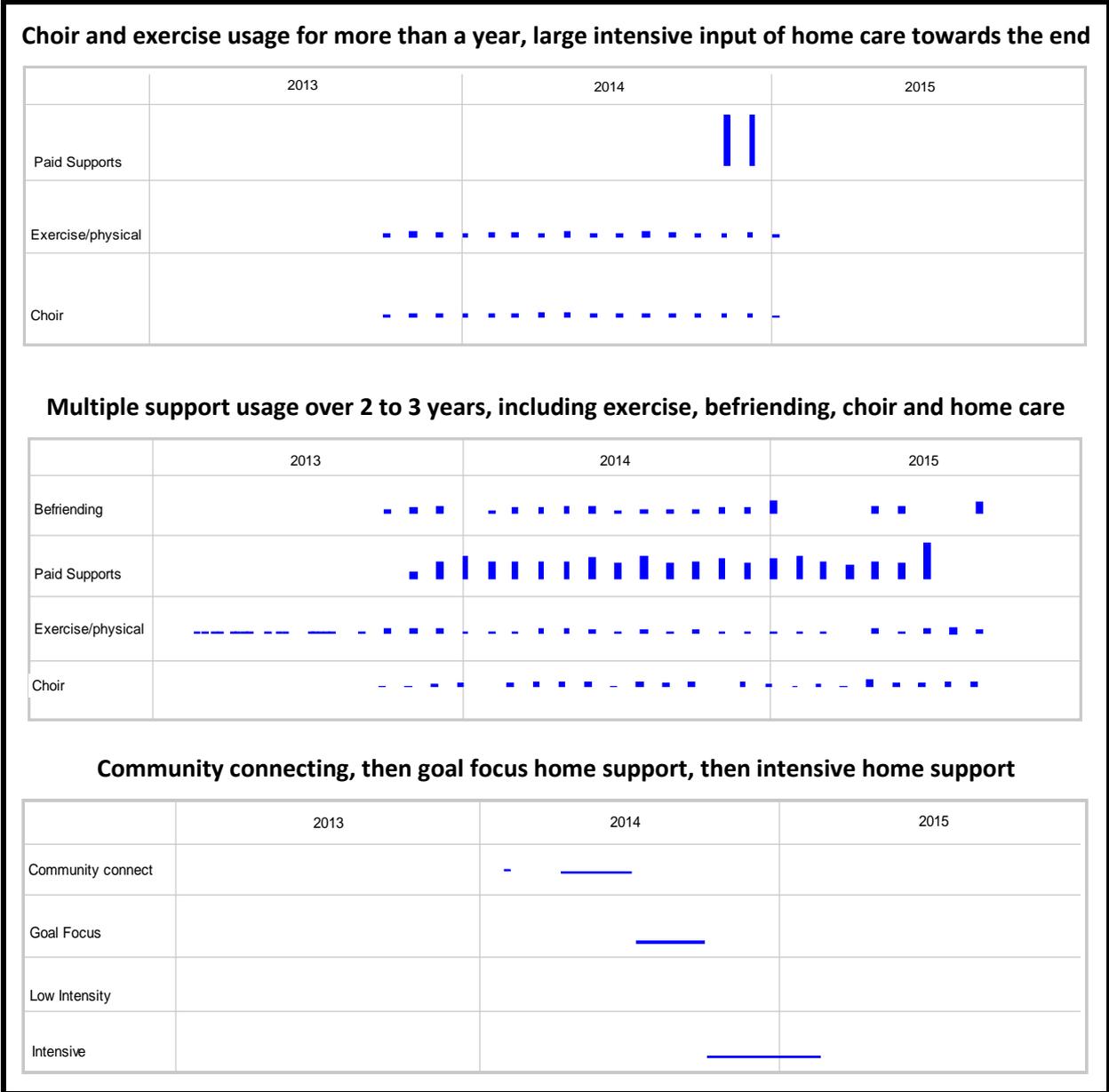
Participants in South Tipperary tended to have longer registration with the project than participants in Stillorgan/Blackrock, as measured in weeks from first registration with the project until they left, or until the end of the project for those who were still registered at the time the project ended. The median registration duration was 101 weeks in South Tipperary and 82 weeks in Stillorgan/Blackrock. Intensity of support usage, measured in hours per week per person over the entire duration they were with the project, tended to be considerably higher in Stillorgan/Blackrock (median = 1.0) than in South Tipperary (median = 0.5).

There was a similar pattern when intensity was measured for the period covering from when a person with dementia first received any support hours until they ceased receiving supports. This 'active' duration is an approximate calculation based on the dates indicated in the database, which did not always allow precise calculation of the duration over which the supports in question were utilised. The approximate 'active' duration extended over more weeks in Stillorgan/Blackrock (median = 53) than in South Tipperary (median = 18), with a median of two hours per 'active' week in

South Tipperary and 1.7 hours per 'active' week in Stillorgan/Blackrock. Reflecting the individual tailoring of support, both projects showed a very broad distribution across participants in total hours and composition of support utilised (Figure 3.1).

Some supports were in a group setting as part of a personalised plan (e.g. exercise, choir), but the largest share was in the form of one-to-one supports (personalised home supports, befriending/connecting). In Stillorgan/Blackrock, for the five core supports provided, paid personalised home support hours comprised more than 60 percent of the total hours, with a small number of people with dementia receiving a very large number of hours of paid home care. In South Tipperary, the two main forms of personalised home support (goal focus/connecting and intensive) comprised almost 90 percent of the total hours provided.

Figure 3.1 Illustrative participant profiles - patterns of support usage over time



Note: height of the bars and/or thickness of the lines indicates the intensity of support (in hours)

3.2 Value for money

Living well with dementia is generally associated with living at home in the community rather than in long-term residential care. For most people with dementia and their carers/families, this is the preferred situation for as long as possible. Nevertheless, many people with dementia eventually move to residential care and this is evident in the proportion of older persons in long-term residential care who have dementia.

Economic analysis

A separately conducted economic analysis of project costs focused on people with dementia identified as having high risk of admission to residential care in the near-term (O'Shea and Monaghan, 2016). It concluded that the projects potentially helped avoid/delay entry to long-stay residential care for many of these individuals. The feedback from family carers presented in Chapter 2 provides a degree of corroboration for this.

As residential care represents an expensive form of care provision, delaying its use can result in substantial cost savings. For the four dementia programme projects combined, the economic analysis estimated potential cost savings of more than €3 million (for 181 people for an estimated period of approximately 15 months) from avoidance/delay of move to long-stay residential care in comparison with HSE community service and project support costs. About one-half of this potential saving accrued from the Stillorgan/Blackrock and South Tipperary projects. These figures point to the potential for significant cost savings across larger numbers of people and/or for longer periods of time.

Whilst the potential savings are substantial, it would be inappropriate to blindly aim to keep persons with dementia at home without considering the best interests of all concerned, both the person with dementia and family carers. For most people with dementia and their families, remaining living at home for as long as possible is a valued outcome in its own right, although the value of this is strongly influenced by supports to live well in everyday life with dementia. Maintaining people with dementia at home for longer also has a cost, particularly for family carers who still provide the bulk of care to people with dementia in Ireland (Connolly et al, 2014). The economic analysis showed the substantial contribution made by family carers that facilitate these care system savings, and the importance of supporting family carers through both standard home care and the types of personalised supports provided by the projects.

Broader value for money

Cost considerations are only one element of what needs consideration when making decisions about types of care that should be available and in what setting. The wellbeing gains for persons with dementia and family carers are a core part of the value case for the provision of individualised and person-centred supports in addition to standard care. At an average of between one to two hours per week per person, the overall levels of additional personalised support provided in these projects were not very large.

Overall, given the substantial wellbeing gains reported by many people with dementia and carers, it seems that relatively marginal additions of personalised supports may generate very high yield. There is a strong case for considering resourcing the provision of low intensity supports that can reach large numbers of people with dementia and their carers, particularly at earlier stages. Nationally, the required resources to mainstream the provision of this form of support, in addition to the 'usual' social care allocation for older people, would appear to be quite modest.

Given the economic case and wellbeing gains, the innovative programmes provide substantial value, not only for the person with dementia and family carer, but also for the wider dementia care system and in supporting achievement of dementia policy objectives. For the community care services, there is considerable value from having something positive to offer people with dementia. For the wider care system, these approaches facilitate fairer sharing of caring between the care system, family carers, and communities more generally. Separately and in combination, the demonstrated impacts and outcomes strongly support the case for mainstreaming these approaches in order to deliver on the objectives of the National Dementia Strategy.

Implementation model

In the two projects, the implementation framework included a coordination function (such as a dementia care coordinator) and provision of a large number of hours of support through a range of individual-based and group-based interventions. HSE professionals led the programmes and were extensively involved in many elements. Home-based supports were delivered in a variety of ways, including paid Dementia Support Workers and a managed pool of trained volunteers. Outsourcing arrangements were a central feature, with HSE funding and quality assuring support services delivered by third parties. Contributions from the community sector and other stakeholders leveraged a significant contribution of in-kind resources and voluntary inputs, but a central organising and funding role by the HSE care services was essential. The *Community Supports Model* describes the wider system utilised for delivery of the individualised and person-centred supports (Genio, 2016). These approaches proved feasible and effective, and could operate in HSE local areas across the country.

4 Conclusions

There is a demonstrated and compelling value case for provision of personalised and person-centred supports as part of community-based care for people with dementia in Ireland. This is underpinned by an extensive range of evidence from the projects and from the wider research literature. The incremental costs, over and above standard care costs, are relatively small and represent good value for money in delivering on dementia policy and the National Dementia Strategy. In addition, there is the potential for substantial savings from delay or avoidance of long-stay residential care costs.

The evidence presented in this report indicates a strong case for resourcing the provision of personalised supports across the trajectory of dementia, with the types of lower intensity and personalised supports provided by these projects having particular relevance. These can be scaled to respond as individual need increases. This approach could reach large numbers of people with dementia and family carers, particularly at an earlier stage. The projects show that it is practically feasible to implement these types of services at local level within HSE community care services. The basic model could be replicated in every area across the country, whilst allowing for tailoring and fine-tuning to local needs and capacities.

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