



Building a  
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Seirbhís Sláinte  
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National  
**Dementia**  
Office

Report of:  
An Evaluation of the HSE's  
National Dementia  
Post-Diagnostic Support  
Grant Scheme

November 2019



NUI Galway  
OÉ Gaillimh



Centre for **Economic  
and Social Research  
on Dementia**

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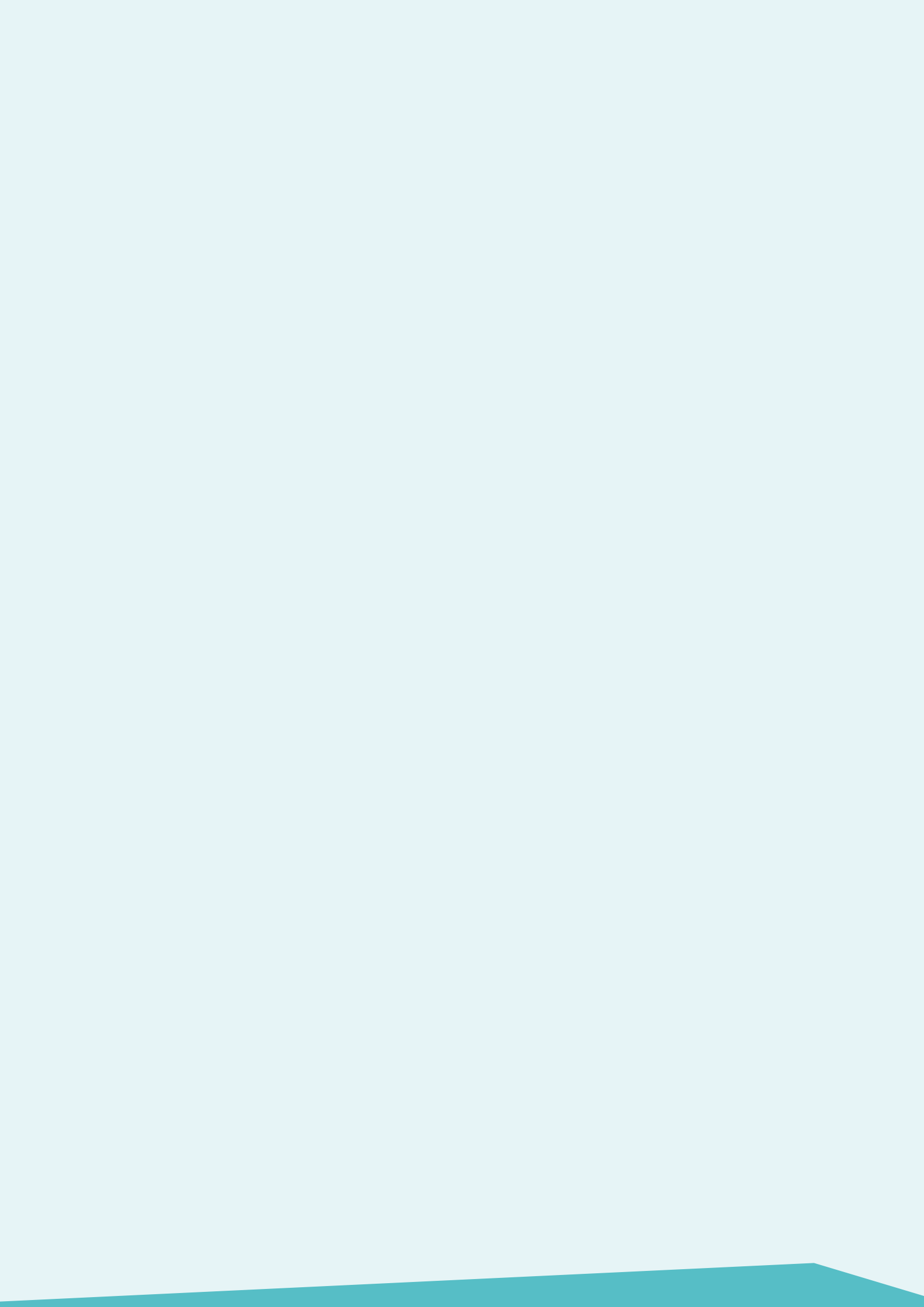
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# Executive Summary

The NDO commenced its first phase of work in the area of post-diagnostic supports for people with dementia in June 2017, referred to as the Dementia Post-diagnostic Support Pathways Project (Department of Health, 2018). For this project, four key pieces of work were completed:

- The NDO, through a scoping exercise, identified: (i) existing good practice in post-diagnostic dementia care and support in Ireland; and (ii) service gaps;
- A review of the international evidence relating to post-diagnostic support was undertaken by the Centre for Economic and Social Research on Dementia (CESRD) (O'Shea, Keogh and Heneghan, 2018). This review collated international evidence on the effectiveness of different PDS interventions and programmes;
- A needs analysis, based on focus groups with people with dementia, was undertaken by the NDO to identify people's opinions, preferences and requirements; and
- A multi-disciplinary and cross-sectoral steering committee was established in an effort to build partnerships and collaborative approaches to post-diagnostic support. This Committee will be tasked with identifying suitable approaches and avenues for roll-out.

Once the first phase of work was complete, the NDO, with funding from Dormant Accounts through the Department of Health, established the Dementia Post-Diagnostic Support (PDS) Programme. This Programme has several elements, including the PDS Grant Scheme, which is the subject of this evaluation. The PDS Grant Scheme aimed to implement new post-diagnostic supports across the country; increase staff capacity to deliver PDS interventions and make them more available to people living with dementia. The Scheme focussed on three intervention types: cognitive stimulation therapy (CST), cognitive rehabilitation (CR) and psychoeducational (PE) interventions. Following an open competition, grants covering staff costs were awarded to 18 applicants (two in each Community Healthcare Organisation) to deliver at least one of these three intervention types over an 18-month period commencing in September 2018.

This evaluation of the Dementia PDS Grant Scheme is an overall assessment of the scheme. Its objectives are to:

- (i) describe the PDS interventions delivered, processes around their delivery, and context within which they were delivered;
- (ii) assess the overall impact of the PDS interventions for the person with dementia and their family members; and
- (iii) assess if the scheme succeeded in addressing post-diagnostic support and care gaps.

As there is an established and growing evidence base for CST, CR and, to a lesser extent, PE interventions, this evaluation did not set out to demonstrate the effectiveness of these approaches. Rather, it focused on issues related to intervention implementation, including facilitators and barriers to change; and assessing the subjective impact of the interventions on people with dementia and their family carers. The evaluation included a process evaluation, based on a desk-based review of grant applications, consultation meetings and interviews with grantees. Data on intervention participants was collected by the grantees as part of their routine service monitoring and evaluation. The impact of the interventions on people with dementia and their family carers was assessed using a short evaluation form, informed by the Eden Alternative Framework of Wellbeing. Ethical approval for this study was granted by the NUIG Research Ethics Committee in December 2018.

The evaluation's data collection period was from January to June 2019. During this time, 17 projects implemented PDS interventions. The majority of projects were based in the HSE, across different HSE divisions, and three were led by a voluntary sector organisation. NDO funding provided support and impetus for the implementation of CST, CR and PE interventions, with the goal of establishing these on a firmer and consistent footing. It is important to note that the grant funding could only be used for staffing purposes and worked best when the funding was allocated to fund an existing senior health professional within the organisation (or service division). In contrast, projects using the funding to recruit new staff experienced delays, highlighting the need for recruitment processes within the HSE to facilitate reform rather than to act as a constraint on innovation.

A total of 232 people with dementia and 140 family carers of people with dementia participated in the PDS interventions between 1 January and 30 June 2019, 89 in CST, 80 in CR and 63 in PE interventions. A total of 140 family carers of people with dementia participated, 64 of whom attended CR with their relative and 76 family carers participated in PE interventions. These overall figures mask the wide-ranging levels of participation among the 19 interventions.

### Participation in PDS interventions January 2019 to June 2019

	No. of people with dementia (all projects)	No. of family carers (all projects)
CST	89	n/a
CR	80	64
PE	63	76
<b>Total</b>	<b>232</b>	<b>140</b>

Findings show that a confluence of staff experience, skills, readiness and know-how, choice of intervention and decisions around adopting an existing intervention or developing a new one, embeddedness of staff within their own organisation and the wider health system locally, and management support all influenced the number of people who could avail of the PDS interventions. The local context including the level of demand and interest among people with dementia was very important.

### Cognitive Stimulation Therapy interventions

Seven projects in the PDS Grant Scheme adopted CST interventions. University College London's 'Making a Difference CST Programme' figured strongly among these projects, signalling its acceptability in Ireland. There is strong evidence internationally that CST can produce significant benefits for people with dementia, suggesting that CST is worth scaling up in Ireland. However, all of the Irish projects made adaptations to existing models, and more attention needs to be paid to how this might impact on efficacy before support can be given to any particular source of variation. Further work is needed to ensure that there is an appropriate level of uniformity and consistency between CST interventions on offer in Ireland and the original models. Staff readiness and flexibility to implement CST also needs to be assessed, and while CST training is important, additional strategies such as expert consultation, ongoing supervision, mentoring and feedback are also needed for less experienced staff.

Findings from the evaluation also show that sharing of CST materials among projects and other health professionals could be explored and facilitated. While the target beneficiaries for CST are usually people with mild and moderate dementia, project staff believed there were also benefits for people with advanced dementia. People with dementia participating in CST rated the intervention extremely positively. They welcomed the opportunity for social interaction and the chance to 'talk', and enjoyed the sessions especially when there was laughter and fun. The peer support offered by CST groups was important, and made participants feel that they were not

alone. The evaluation has also shown the feasibility of providing CST to in-patients with dementia in an acute hospital setting, especially in the context of long in-patient stays, as one of the funded CST programmes was based in an acute setting.

### **Cognitive Rehabilitation interventions**

International evidence on CR, while not yet definitive, is growing, and suggests that CR has the potential to form a valuable component of PDS for people with dementia. While the best available evidence on the effectiveness of CR currently relates to individual, goal-oriented CR, the projects in the PDS Grant Scheme tended to opt for memory rehabilitation, a more structured form of CR, which places a greater emphasis on strategies than on individual goals. One example of this is Home Based Memory Rehabilitation (HBMR), which is prevalent in Northern Ireland and Scotland, especially among OTs. Generally, delivering memory rehabilitation as a group intervention was also popular, allowing peer support to emerge as well as being cheaper to run. The use of memory aids was also prevalent among the projects delivering CR, but as funding from the NDO could not be used for this purpose, access to memory aids was variable across projects.

People with dementia participating in the CR interventions evaluated them very positively. They found the information and advice received practical. They found the tips and strategies helped them to manage everyday tasks and most agreed that the intervention gave them more confidence in doing this. With respect to the group interventions, peer support was identified as an important element and participants valued the feeling of reassurance from being connected with health services staff and knowing that there is someone there to support them.

### **Psychoeducational interventions**

There are benefits associated with PE interventions, and the need to tailor such interventions to people at the early stage of the care trajectory following a dementia diagnosis has been highlighted in the literature. All but one of the funded projects was establishing new PE interventions, which is a really significant undertaking in terms of time and resources and requires a good deal of expertise.

The Dementia Services Information and Development Centre's (DSIDC) Next Steps Guidance Document on Psychoeducational Programmes (Gibb et al., 2019) was highlighted as an important and practical tool to guide those developing PE interventions. There was huge variability across the PE interventions in this study, each being quite different from the others, with varying aims, content, target beneficiaries, mode of delivery and settings. All of the PE interventions included an education component, but the educational content covered varied hugely. The extent to which the interventions supported participants to manage circumstances related to dementia such as emotional response or stress also varied. Without a detailed evaluation of the various PE interventions, it is difficult to comment on the constituent components of the interventions and what works best for whom and in what circumstances. In terms of recruitment and take-up, individual, dyadic PE interventions were more successful than dyadic group PE interventions. Responses by people with dementia and family carers to the PE interventions were very positive.

### **Staffing and staff competencies**

Staff implementing and delivering CST and PE interventions came from a range of disciplinary backgrounds. In contrast, the majority of staff delivering CR interventions were OTs. The successful implementation of PDS interventions did not so much depend on the disciplinary backgrounds of staff, but on the motivation, experience and skills of staff. All three elements are important and should not always be assumed to co-exist. Across all three intervention types, it was important for staff to have knowledge of dementia, training in dementia care, and experience of working with people with dementia. It was also important to have experience of,



and the skills and abilities for planning and implementing psychosocial interventions. For group interventions, staff experienced and skilled at facilitating group work with people with dementia was vital to intervention success.

The characteristics of the 'team' implementing interventions was also important. Findings from the evaluation show that successful teams were highly motivated, well organised and tightknit, with excellent working relationships. For implementation to be a success, these teams needed to work with a wide range of people within their own organisations as well as people outside of their organisation.

Implementing PDS interventions takes work and the time taken to implement PDS interventions and engage stakeholders should not be underestimated. However, through the PDS Grant Scheme, there is now a cohort of experienced personnel around the country, who, if these interventions are to be scaled up, could potentially support and mentor other health professionals to implement psychosocial interventions. This opportunity to leverage future progress on the back of the lessons learned on this scheme and the expertise of the first tranche of innovators should not be lost.

### **Venues**

Interventions were delivered by the projects in a wide range of venues. Finding rooms could be challenging and time-consuming, and while most rooms worked out well, some had physical, environmental and aesthetic constraints. The ability to use rooms in HSE buildings was regarded as a great resource for the projects in the study. PDS interventions delivered in rooms located on hospital groups appeared to have more credibility among people with dementia and their family carers and attracted higher numbers of participants. The use of Memory Technology Resource Rooms (MTRR) for delivery of PDS interventions represents a potential good use of the MTRR resource.

### **Dementia diagnosis and diagnostic issues**

The evaluation has highlighted several pertinent questions and issues relating to dementia diagnosis including direct linkages with diagnostic services, referral pathways between diagnostic and post-diagnostic services, diagnostic disclosure, stigma and lack of insight. The evaluation shows that successful delivery of PDS interventions requires a level of commitment from family carers, including getting people with dementia to and from a venue. This evaluation also highlighted practical access issues such as parking and way-finding, and the important support role played by staff working within buildings where PDS interventions were held. This highlights the need for reforms, including adaptations within the built-environment to support the inclusion of people living with dementia.

### **Concluding remarks**

In summary, the overwhelming majority of people with dementia who participated in the CST, CR and PE interventions had very positive experiences. The interventions were of enormous value to those that participated directly and for their families. Those providing the interventions also reported significant value added, not only for recipients, but also in relation to overall care objectives including staff morale and satisfaction. The evidence is strong enough for the HSE to consider allocating additional resources towards the development of a wider and deeper programme of post-diagnostic supports for people with dementia and their families.

# 1. Introduction

This is a report of an evaluation of the National Dementia Office's (NDO) Post-diagnostic Support Grant Scheme, which forms part of the implementation of the Irish National Dementia Strategy (NDS) (Department of Health, 2014). The Strategy seeks to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society.

Post-diagnostic support is not directly referenced in the NDS, but is incorporated into the Strategy through its priority action area 'Timely Diagnosis and Intervention'. With regard to this priority area, the NDO has taken several actions to support the implementation of the NDS in two phases. A first phase of work, known as the Dementia Post-diagnostic Support Pathways Project, was commenced by the NDO in June 2017 (Department of Health, 2018). For this project, four key pieces of work were completed:

- The NDO, through a scoping exercise, identified (i) existing good practice in post-diagnostic dementia care and support in Ireland and (ii) service gaps.
- A review of the international evidence relating to post-diagnostic support, undertaken by the Centre for Economic and Social Research on Dementia (CESRD) (O'Shea, Keogh and Heneghan, 2018). This review collated international evidence on the effectiveness of different PDS interventions and programmes;
- A needs analysis, based on focus groups with people with dementia, undertaken by the NDO to identify people's opinions, preferences and requirements; and
- A multi-disciplinary and cross-sectoral steering committee was established in an effort to build partnerships and collaborative approaches to post-diagnostic support.

Once the first phase of work was completed, the NDO, with funding from Dormant Accounts, established the PDS Programme. This Programme aimed to increase capacity within the system to deliver post-diagnostic support and provide guidance for service and support intervention. The programme has several elements, including the development of a National Dementia Café Network; the development of a national PDS framework, the provision of Cognitive Rehabilitation Master Classes and the development of the Next Steps Guidance Document focusing on psycho-education for people living with dementia (Gibb et al., 2019). The PDS Grant Scheme, the subject of this evaluation, is also an element of this programme.

The PDS Grant Scheme provided funding for the delivery of three PDS intervention types, namely: cognitive stimulation therapy (CST), cognitive rehabilitation (CR) and psychoeducational (PE) interventions. Following an independent review of applications, grants covering staff costs were awarded to 18 applicants (two in each Community Healthcare Organisation (CHO) area) to deliver at least one of these three types of post-diagnostic support interventions over an 18-month period commencing September 2018.

This evaluation of the Dementia Post-diagnostic Support Grant Scheme, commissioned by the National Dementia Office (NDO), is an overall assessment of the scheme. The objectives of the evaluation were:

- to describe the PDS interventions delivered, processes around their delivery, and context within which they were delivered;
- to assess the overall impact of the PDS interventions for the person with dementia and their family members; and
- to assess if overall the scheme succeeded in addressing post-diagnostic support and care gaps.

## 2. Background and context

### 2.1 The need for post-diagnostic support

The commencement of the NDO's Post-diagnostic Supports Pathways Project in 2017 addresses an important element in the provision of care to people with dementia (O'Shea and Keogh, 2017). At an international level, post-diagnostic support is directly referenced in the World Alzheimer Report (ADI, 2011) and the World Health Organization (WHO) report (WHO, 2012) in their seven-stage model for planning dementia services. Rees (2017), reflecting on care for people with dementia internationally and identified post-diagnostic support as a fundamental policy issue in dementia care for policymakers and governments.

The case for post-diagnostic support has been strengthened by the growing evidence on the importance of a timely diagnosis of dementia and increasing recognition that people who receive a diagnosis of dementia can benefit from post-diagnostic support (O'Shea and Keogh, 2017; O'Shea, Keogh and Heneghan, 2018). The need to take action on developing post-diagnostic support for people with dementia is amplified by Ireland's population ageing, as like other countries, Ireland is witnessing significant increases in the number of people with dementia that will continue over the coming decades (Pierce and Pierse, 2017). The publication and implementation of the NDS has focused attention on the timely diagnosis of dementia through the education and training of GPs and other primary care professionals under the PREPARED project (2016-2018), and by work undertaken as part of the Dementia Diagnostic Project, established by the NDO in Autumn 2017. The latter aims to establish a standardised approach to the assessment and diagnosis of dementia across primary, secondary and tertiary services. Public awareness about dementia has been heightened by the Understand Together campaign launched in 2015 (Glynn et al., 2017) and it is reasonable to assume that an awareness programme of this magnitude together with the growing prevalence of dementia and a trend towards earlier dementia diagnosis will lead to increased demands for post-diagnostic support in the coming years.

While the PDS Support Grant Scheme is closely linked to the NDS, it is but one of a wide range of documents and reports in a rich health policy landscape that have supported new investment in services and supports. Of particular note is the Sláintecare report, published in 2017, which sets out a high-level policy roadmap for health care reform. A key aim of Sláintecare is the reorientation of the health system towards 'integrated primary and community care', including a restructuring of primary and community care services. Deficits in post-diagnostic support for people with dementia was highlighted in submissions to the Sláintecare Report, along with deficits in other community-based supports (Oireachtas Committee on the Future of Healthcare, 2017).

The reframing of dementia in broader social terms beyond the biomedical perspective, which has traditionally shaped policy and practice responses, has been an important shift in dementia care in Ireland and internationally (Cahill, 2017), especially in relation to post-diagnostic support. Central to the social model of dementia is the notion that with the right interventions and supports, it is possible to maximise the capabilities experienced by people with dementia and support the person and their family to live a good life in a more inclusive society. The biopsychosocial model is also person-centred and is in alignment with reablement, a strengths-based approach. Rather than honing in on the deficits and declines associated with the condition, reablement seeks to build on the strengths and retained abilities of people with dementia, thereby promoting autonomy, independence, choice and control. The conceptualisation of dementia as a disability brings a rights-based approach to the fore and

compliance by Governments with the United Nations Convention on the Rights of Persons with Disability (UNCRPD) (Cahill, 2017; 2018), which is encouraged by the WHO (2012). The UNCRPD outlines the right to rehabilitation for people with disabilities (Article 26.1), and this includes cognitive rehabilitation for people with dementia (Clare, 2017, Cahill, 2017; 2018). The biopsychosocial approach can also be applied to psychoeducational interventions in the area of dementia and these interventions can include education on rights.

While there is no single definition of post-diagnostic support, a formal definition provided by the Social Care Institute of Excellence (SCIE) is: “to help people continue living well in the community; provide information and support; help people to manage issues as a result of getting a diagnosis; and delay admission to long-term residential care” (SCIE, 2014: 2). The National PDS Steering Group defined post-diagnostic support as: “To enable and assist people with dementia and their families to live a life of their choosing throughout the continuum of dementia. Post-diagnostic supports include interventions, therapeutic treatments and activities that build on strengths and abilities; helping to maintain and enhance quality of life” (2018). The importance of targeting PDS specifically to people with dementia has been highlighted internationally (Mountain and Craig, 2012). Consequently, O’Shea and Keogh (2017: 88) have argued that post-diagnostic support ‘should, therefore, be eclectic in its origins and ambitions, focusing on the disease, the people that have it and their carers’. Given that a dementia diagnosis does not come at a set time/stage, or age for people with dementia, the importance of providing post-diagnostic support that is personalised and responds to the expressed needs of the person diagnosed has also been emphasised (O’Shea and Keogh, 2017).

## **2.2 Evidence on and availability of post-diagnostic supports**

O’Shea and Keogh (2017) loosely divide post-diagnostic support into four categories: information, advice and peer support; cognitive therapies; psychoeducational support for carers; and psychosocial supports. This section provides a brief overview of the evidence relating to post-diagnostic support, and comments on their availability. For the purposes of this report, this overview is confined to cognitive therapies (which includes CST and CR), and psychoeducational support, as these were the categories of supports funded by the NDO under its PDS Grant Scheme. A more in-depth review of the international evidence on post-diagnostic support can be found in O’Shea, Keogh and Heneghan (2018) and Keogh et al. (2019).

### **2.2.1 Cognitive Stimulation Therapy**

Cognitive stimulation is a cognitive-based non-pharmacological intervention that targets cognitive and social function (Clare et al., 2003). Its roots lie in reality orientation. The activities at the core of cognitive stimulation interventions are aimed generally at stimulating cognitive abilities such as memories and thinking. The range of activities includes discussion of past and present events and topics of interest, word games, music and practical activities. Cognitive stimulation interventions are usually undertaken in a group setting with small groups of people with dementia and are typically facilitated by trained staff. Cognitive stimulation is an intervention with robust evidence. It has been established that the use of cognitive stimulation interventions with people with mild and moderate dementia is beneficial for improving cognitive function and quality of life (Livingston et al., 2005; Olazaran et al., 2010; Woods et al., 2012; NICE, 2018). Due to the progressive nature of the condition, long-term benefits may be limited (O’Shea, Keogh and Heneghan, 2017).

Cognitive stimulation therapy (CST) adopts a person-centred approach, which requires the intervention to be implemented in a sensitive, respectful and person-centred manner. One of the most comprehensive, ubiquitous and rigorously researched CST interventions described in the literature is the Making a Difference CST Programme (<http://www.cstdementia.com/>), developed at University College London (UCL) following the Medical Research Council (MRC) framework for the development of complex interventions (Aguirre, Spector and Orrell, 2014). It follows a set of principles that must be incorporated into the programme, including mental stimulation,

opinions rather than facts, triggers to aid recall, continuity and consistency between sessions, engagement and involvement, inclusion and fun. CST is a brief intervention, designed around 14 themed sessions, each lasting up to one hour, usually delivered twice weekly over seven weeks. The programme is now used globally and across 29 countries.

Several randomised controlled trials (RCTs) have been conducted to test the benefits of CST. Using such trials, CST has been shown to be effective with regard to cognition and quality of life (Spector et al., 2003), and there is evidence of its effects on different areas of cognitive function for people with dementia. CST appears to be particularly effective in promoting language function, and may therefore help with communication and conversation, enabling the person with dementia to express their opinions, which in turn may impact positively on preference revelation and well-being. It is not unusual for the 14-session intervention to be delivered once weekly over 14 weeks instead of seven. While one study found that a once-weekly format was not effective, suggesting that dose is important (Cove et al., 2014), this was inconsistent with the findings of an Irish study of CST, which reported benefits (Kelly et al., 2017). Notwithstanding the evidence, changing to a once-weekly format may be necessary where there are time constraints and resource limitations and/or to meet participant availability (Cove et al., 2014). The characteristics of participants also seems to matter, highlighting the importance of taking account of age, gender, and living situation of participants when designing CST for best effect (Aguirre et al., 2013; O'Shea, Keogh and Heneghan, 2017).

There are very few studies investigating the cost-effectiveness of CST (O'Shea, Keogh and Heneghan, 2017), but from their study conducted as part of an RCT, Knapp et al. (2006) concluded that CST is potentially more cost-effective than treatment as usual. The continuation of CST, through maintenance CST, is also likely to be cost effective for people with dementia (D'Amico et al., 2015).

There is also qualitative evidence to support the use of CST in routine practice for people with mild to moderate dementia. Spector, Gartner and Orrell (2011) explored the views of people with dementia, along with those of family carers and group facilitators, on the impact of CST. Benefits were reported by all three groups. The benefits related to the positive experience of being in a group, and the positive impact of participation on everyday life. Participating in the CST group was reported to be enjoyable and fun. People with dementia looked forward to attending and were sorry when it came to an end. Attending the group left people feeling more relaxed, positive and confident. They liked having an opportunity to hear each other's views, and that the group helped them overcome feelings of isolation. Being with others who shared a common difficulty was seen as supportive. Improvements reported by people with dementia, their family carers and group facilitators included being able to talk more easily in the group environment, improvements in memory, alertness and concentration.

CST has mainly been provided to people with dementia residing in long-stay residential care settings or those living in the community, but it can also be provided to in-patients with dementia in an acute hospital setting. The hospital setting presents particular challenges for the delivery of CST, and, although evidence is lacking as to the intervention's effects in such a setting, feedback from people with dementia and hospital staff has been positive (McAulay and Streater, 2019).

Cogs Club is a separate intervention that has been developed by Jackie Tuppen to provide cognitive stimulation for people with dementia (<https://www.cogsclub.org.uk/home/>). It is linked to CST in that it is informed by the evidence on CST and guided by the same principles. Cogs Club, like CST, is structured and uses thematic sessions, but a major difference between it and CST is that the one-hour session is extended to a day of activity, music and fun. In this way, CogsClub aims to provide people with dementia with an alternative to traditional day care or respite, whilst at the same time providing family carers with a break from caring. This intervention has not been rigorously tested in the way that CST has been, but feedback from intervention participants is positive (Tuppen, 2010).

CST training has been identified as an urgent priority to enable the implementation of CST. To support CST implementation in practice, a comprehensive training package has been developed by the intervention developers. A CST training manual and DVD on how to offer the intervention has been developed and includes the key principles of CST, a session-by-session plan, details of the equipment needed and ways of monitoring progress. A formalised CST training day, which covers the theoretical and research background to dementia and CST, and its practical delivery and implementation in practice, has also been developed (Streater et al., 2017). An International Centre for CST has been set up to coordinate work on this intervention and evidence-based guidelines have been developed to guide the adaptation to other cultures and have been used for example in India, Japan and Tanzania (Aguirre, Spector and Orrell, 2014).

In the UK, CST is regarded as a standard post-diagnostic support that should be offered routinely to people with dementia (Keogh et al., 2019). This can be largely attributed to its endorsement by the National Institute for Clinical Excellence (NICE) in their guidelines for cognitive symptoms and maintaining function in dementia (NICE, 2006; 2018). The guidelines recommend the use of group cognitive stimulation as a form of dementia management, regardless of drug treatment. Furthermore, CST is included in the Standards for Memory Services developed by the UK's Memory Services National Accreditation Programme (MSNAP), which aims to improve assessment, diagnosis and care for people with dementia and their carers. Specifically, Standard 6.2.1 (a Type 1 standard<sup>1</sup>) recommends that 'patients have access to a local programme of age appropriate group cognitive stimulation therapy (CST)' (Copland et al., 2018). Accordingly, the standards encourage memory services to offer CST or have access to CST provided elsewhere in the community to which they can refer people following a diagnosis of dementia. Memory services are also expected to give people with dementia access to maintenance CST. Individual CST is included as an aspirational standard for memory services (Copland et al., 2018).

The availability of CST in Ireland stands in stark contrast to the UK. It is currently not routinely available to people with dementia in the country (Kelly et al., 2017). Although CST is not completely alien to Ireland's dementia care landscape, like many countries in Europe, it has mainly been provided in residential long-term care facilities and day care settings (Alzheimer Europe, 2014), although community-based CST has been piloted and its efficacy tested (Kelly et al., 2017). The efficacy of CST has also been tested in another small-scale Irish study (Coen et al., 2011). While we do not have baseline information on the availability of CST in Ireland, it is reasonable to say that its availability prior to the current scheme has been low.

### 2.2.2 Cognitive Rehabilitation

Cognitive rehabilitation has been described as an approach that focuses on improving cognitive functioning in everyday life and supporting people to achieve the everyday goals that matter to them (Bahar-Fuchs et al., 2013). A well-researched form of CR is individual goal-oriented cognitive rehabilitation, which originated at the University of Bangor in North Wales. In this intervention, people with dementia work together with a trained health professional over a number of sessions to identify goals that are personally relevant and seek to achieve these by devising and implementing strategies. Family carers often also attend the sessions. Goals identified may include remembering recent events, reducing repetitive questioning, remembering people's names, or remembering upcoming events (Clare et al. 2003). Assistive technology or memory aids may be used to provide environmental prompts.

<sup>1</sup>The criteria associated with Type 1 standards is as follows: failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law. These standards also include the fundamentals of care, including the provision of evidence-based care and treatment (Copland et al., 2018).

There is limited but growing evidence on the effectiveness of CR. The first pilot RCT on cognitive rehabilitation was conducted by Clare et al. (2010) comparing individual, goal-oriented CR to relaxation therapy and to a no treatment control group. It found CR to be superior in the short-term to usual care in relation to participant-reported improvement in goal performance and satisfaction. Results from a later study by Kim et al. (2015) were consistent with these findings. More recent evidence comes from the GREAT trial involving 475 people with dementia, which was designed to provide definitive evidence on the effectiveness of CR for people with dementia (Clare et al., 2019). In the GREAT trial, goal-oriented CR was provided on an individual basis in the home of the person with dementia. It consisted of 10-weekly one-hour sessions over a three-month period followed by four one-hour maintenance sessions delivered over six months. In addition to working with the individual to choose rehabilitation goals, the intervention included the use of emotional regulation and behavioural strategies to address motivational and emotional difficulties as needed, reviewing and optimising participants existing strategies, and providing practice in maintaining attention and concentration.

Based on participant-reported improvement in goal attainment, the CR intervention was found to be effective in improving functioning in the targeted areas at three months from the perspective of both participants and study partners, and this improvement was maintained at nine months. Participants with higher socio-economic status had better outcomes. The main conclusion from the GREAT trial is that individual, goal-oriented CR enables people with dementia to function better and more independently in relation to goals targeted in the therapy (Clare et al., 2019). Since the volume of evidence on CR is increasing, a systematic review is currently underway to update and provide a high level of evidence on its effectiveness (Kudlicka et al., 2019).

Another form of CR is Home-based Memory Rehabilitation (HBMR), an Occupational Therapy-led programme of memory rehabilitation for people with dementia. It was created in 2007 by Mary McGrath, an Advanced Clinical Specialist Occupational Therapist based in Belfast City Hospital, Northern Ireland (McGrath and Passmore, 2009; McGrath, 2013). The intervention is designed to be an early intervention, which aims to help people with mild dementia compensate for memory difficulties affecting everyday functioning. It emphasises structure and repetition to encourage new learned behaviours in early stages of dementia, and promotes habits and routines, with the understanding that these are more likely to be remembered as memory loss continues. The HBMR intervention is structured around six sessions which take place in the person's own home. Each session focuses on a specific topic e.g. remembering priorities such as taking medication, remembering what people have said, coping in social situations, keeping the brain healthy, orientation and driving. At each session, tips are given and strategies for compensating for memory difficulties practiced. External memory aids including a memory book, medication checklist, calendar and memory board are introduced sequentially. After the intervention ends, review meetings are held with participants at regular intervals. The primary outcome measure for this programme is the number of strategies in use at three months. Findings are that intervention participants are using an average of six strategies at three months compared to an average of two at initial assessment (McGrath, 2019). Little other evidence is currently available on the impact or effectiveness of this intervention.

Neither goal-oriented CR nor HBMR have been endorsed by the NICE guidelines, but individual goal-oriented CR is included as an aspirational standard in the Memory Services National Accreditation Programme (MSNAP) Standards for memory services. There appears to be interest among memory services in the UK to offer CR following a diagnosis of dementia (Clare et al., 2013). Northern Ireland has been described as 'in the vanguard of provision of occupational therapy-led memory rehabilitation' (Cunningham et al., 2019). The HBMR intervention has been adopted in each of the Health and Social Care Trusts in Northern Ireland, where it is to be evaluated in the future. In Scotland, HBMR was identified in a national scoping exercise with allied health professionals in 2014 as an intervention that OTs would like to promote as best practice. A HBMR resource pack has been developed by the Mental Health

OT Services in Dumfries and Galloway and the OT HBMR (Scotland) programme piloted in 11 areas across Scotland. There are plans to roll out the programme nationally and make it available to every person newly diagnosed with dementia in Scotland. Plans are also afoot to evaluate the programme's impact (Chambers and McKean, 2017).

Baseline information is lacking on the availability of CR in Ireland, but it is known to be under-provided. Where CR has been available, it has tended to be in the form of small-scale, disparate interventions, often delivered sporadically by individual health professionals, usually psychologists or occupational therapists (Cahill et al., 2012). Some steps have been taken to encourage healthcare professionals to provide CR and equip them with the skills to do so. For example, based on the strategies incorporated into goal-oriented CR, TCD in conjunction with ASI has devised a manual to provide healthcare professionals with strategies and techniques that can be used to assist people with memory problems in optimising management of their daily lives and activities (Kelly and O'Sullivan, 2015). In 2018, the NDO, in collaboration with Engaging Dementia, ran four Cognitive Rehabilitation Therapy Master Classes, as part of the Dementia Post-diagnostic Project. The master classes were facilitated by Mary McGrath and 111 Health and Social Care Professionals attended.

### 2.2.3 Psychoeducational interventions

PE interventions are distinct from support groups and they are also distinct from straightforward educational or information groups. Psychoeducational (PE) interventions combine two key components: an education component and a therapeutic component. The education component focuses on imparting clear and specific information and knowledge about different aspects of the condition, in this case dementia. This could include, for example, information and advice about dementia symptoms, treatment and prognosis; legal and financial issues; driving; nutrition; physical activity; and local supports and services. The therapeutic component focuses on supporting participants to manage circumstances related to the condition and/or other circumstances in their life that may become exacerbated by the condition. This may involve helping people to build skills such as developing effective ways of coping with stress. It may involve supporting people to modify their responses or reactions, for example, overcoming negative emotions following a diagnosis. It may involve supporting people to manage pre-existing challenges in their life in the context of dementia. The approach taken and what is covered by this second component is informed by the psychological theory underpinning the PE intervention, which is also linked to the expected outcomes. PE interventions that are underpinned by clearly defined psychological theory tend to be more effectively targeted and delivered (Milne et al., 2014). PE interventions can be targeted at either family carers, people with dementia, or dyads (people with dementia and family carers) and can be adapted for individuals, families or groups. While the education component is often easily managed in a group setting, the therapeutic component can be more challenging in a group setting.

Traditionally, PE interventions have largely been targeted at family carers. Family carers usually provide most of the care to people with dementia, and they often do so over many years. It is hard to define an exact point in time when the need for care by people with dementia begins and family caregiving commences, as this is highly variable. For some people with dementia, the need for support can precede a formal diagnosis of dementia. Regardless of when the onset of care begins, for both the person with dementia (the care recipient) and family carer (caregiver), the transactions connected to giving and receiving support and care are often highly dynamic, unpredictable and change over time. The WHO describes how the caregiving role typically evolves as the person's condition progresses through different stages of dementia, and states that it is important that appropriate interventions take place along the continuum of care from the time of diagnosis through to end-of-life (WHO, 2012).

For the family carer, providing care to a person with dementia can be physically and emotionally demanding and is associated with high levels of caregiver burden and depression (Cahill and Shapiro, 1997; Brennan et al., 2017; Lafferty et al., 2016). In recognition of this, different



support services and interventions such as psychoeducational (PE) interventions have been developed to support family carers providing care to people with dementia. Drawing definitive conclusions from the evidence on the effectiveness of PE interventions for family carers is not straightforward, because the interventions are sometimes sketchily described and there is much variation across interventions along a range of dimensions (e.g. underpinning psychological theory, target beneficiary, format, mode of delivery, content, expected outcomes). Nevertheless, several studies have revealed the benefits associated with PE interventions for family carers including helping to reduce caregiver burden, enhancing emotional wellbeing and reducing depression and anxiety (O'Shea, Keogh and Heneghan, 2018).

The WHO recommends that PE interventions should be offered to family and other informal carers providing care to people with dementia at the time that the diagnosis is made (WHO, 2012). This is because a diagnosis of dementia can bring about many significant and unexpected life changes and at this stage the need for information and education about the condition, and support to cope with the diagnosis are high (Whitlatch et al., 2018; Ducharme, 2011). However, few studies have focused on PE interventions for family carers at this early stage (ADI, 2011; Ducharme, 2011; Ducharme, 2014). Moreover, many PE interventions take a broad-brush approach and are not tailored to meet the needs of family carers at particular stages of the care trajectory (Ducharme, 2011). In a review of qualitative evidence, The National Collaborating Centre for Mental Health suggested that PE interventions can be effective in reducing the risk of depression and bolstering skills among carers when offered early in the dementia trajectory (NCCMH, 2007). An example of a PE intervention sensitive to family caregivers needs following a diagnostic disclosure of dementia is a Canadian intervention which used role transition model as the theoretical framework and consisted of seven weekly individual sessions (Ducharme, 2009; 2011). The evaluation reported that intervention participants had greater confidence, were better prepared to provide care and showed greater self-efficacy in comparison to those in a control group.

Evidence suggests that PE interventions are most beneficial when specifically targeted at family carers and separately from the person with dementia (Milne et al., 2014). Evidence also suggests that PE interventions are most beneficial when the support is tailored to the specific needs of the group (e.g. at the early stages of the trajectory), includes a mix of education, support and skill building and is easily accessible, time limited and low cost (O'Shea et al., 2018).

While PE interventions, as shown above, are mostly designed for family caregivers as the target beneficiary, Gibb et al. (2019) assert that such interventions should also extend to people with dementia. An example of a PE intervention targeted specifically at people with dementia is the 'Living Well with Dementia Programme', developed in the UK as a group intervention delivered over 10 weekly sessions by nurses from a memory clinic. The intervention incorporated education elements (e.g. information about memory loss, dementia and medical treatments) and elements of psychotherapy (e.g. a focus on encouraging participants to share feelings associated with dementia such as embarrassment, worry and sadness) (Marshall et al., 2015).

The social contextual model contends that including both the person with dementia and family carer is important to minimise a potential decline in the quality of the care relationship, or physical and psychological wellbeing of either party, that may result from miscommunication or misunderstanding between the dyad (Moon and Betts Adam, 2012). An example of a dyadic PE intervention is Memory Club, originally developed in the US by Zarit et al. (2004), as a structured, time-limited psychoeducational group for people with early symptoms of dementia and their supporting family member. This is a 10-session intervention designed for 8 to 10 dyads, with sessions held every second week. The aim of Memory Club is to empower both family carers and the person with dementia to participate jointly in managing current problems and planning for the future. The groups are facilitated by a team consisting of a social worker and a neuropsychologist. The social worker covered the educational component, providing information on resources available for people with dementia and their families, while the

neuropsychologist delivers the psychological component by interpreting symptoms and diagnostic findings.

O'Shea and Keogh (2017) maintain that dementia education must become part of Ireland's care landscape to help people cope with the condition and its current and future implications. In Ireland, organisations such as the Alzheimer Society of Ireland (ASI), the Dementia Services Information and Development Centre (DSIDC) and projects funded through the HSE & Genio Dementia Programme have been making in-person training available to family carers. Online training programmes for family carers have been developed by Dublin City University (DCU) Dementia Elevator Programme and the ASI. While the content and mode of delivery of these interventions differs, a common characteristic is that all have been developed solely for family carers. None, as far as we are aware, are specifically targeted at family carers at the early stages of the care trajectory.

Greater attention has recently been brought to the provision of dyadic group PE intervention for early intervention in dementia through the development of a guidance document on psychoeducational programmes by the DSIDC (Gibb et al., 2019). This document was commissioned by the NDO as part of the Dementia Post-diagnostic Support programme of work and aims to support health professionals in the establishment, organisation and ongoing facilitation of post-diagnostic PE interventions for people with dementia and their care partners. It presents the available evidence and outlines good practice in relation to PE interventions for early intervention in dementia. It provides practical considerations on how to run these interventions and gives suggestions for session content. People with dementia and family carers provided insights which helped to shape this document.

In summary, it is clear that there is credible international evidence on the effectiveness of CST for people with dementia which indicates that its use can produce significant benefits. The strength of the evidence base is sufficient to support implementation of CST interventions. Evidence on CR, while not yet definitive, is growing with a recent trial concluding that individual, goal-oriented CR enables people with dementia to function better and more independently in relation to goals targeted in the therapy (Clare et al., 2019). Further studies are underway in this area, and CR has the potential to form a valuable component of PDS for people with dementia. There are also benefits associated with PE interventions, and the need to tailor such interventions to people at the early stage of the care trajectory following a dementia diagnosis has been highlighted. Despite the evidence as to the effectiveness and benefits of PDS interventions, their availability and take-up in Ireland has been slow. This is the context within which the NDO awarded grants to 18 applicants to implement at least one of three different intervention types, i.e. CST, CR and/or PE interventions.

### **2.3 Terminology**

There is no single definition of the term post-diagnostic support and it can mean different things. In Scotland the term usually refers to the support that people get in the 12 months following a diagnosis of dementia, whereas the Irish Dementia Post-Diagnostic Steering Group has defined post-diagnostic support as 'enabling and assisting people with dementia and their families to live a life of their choosing throughout the continuum of dementia'. Furthermore, the word 'support', in addition to specific interventions such as CST, CR and PE interventions, can potentially cover many other supports, including practical task-based help and informational or psychological/emotional support. Because of differing periods of time that may be covered and the range of supports that might be included, the term post-diagnostic support can be perplexing, and it might be less confusing and more appropriate to use the term psychosocial interventions when referring to CST, CR and PE interventions. However, for the purposes of this report and to be consistent with the PDS Grant Scheme, and other international publications (WHO, 2018) we adopt the term post-diagnostic support as an umbrella term to refer the three types of interventions implemented through the PDS programme, i.e. CST, CR and PE interventions.

## 3. Methodology

### 3.1 Approach to the evaluation

Given that there is an established and growing evidence base for CST, CR and, to a lesser extent, PE interventions, it was not the aim of this evaluation to demonstrate the effectiveness of these approaches. The resources were not available to conduct individual evaluations and, in any case, the existing international evidence was accepted as justifying the approach taken by the NDO to award grants covering the three types of intervention.

While evidence of effectiveness is growing, little is known at a practical level from research generally about how PDS interventions are adopted or how they are implemented and adapted in real world practice settings (Boersma, 2015; Orrell, 2012). A key focus of this study is, therefore, on implementation issues, including facilitators and barriers to change. The case for further research into implementation challenges, including the practicalities and fine-grained details of how interventions unfold in the real world, has been compellingly made (Greenhalgh and Papoutsis, 2018). This is important because the impact and effectiveness of the intervention will be shaped by the way it is implemented. Moreover, the impact of an intervention is likely to be shaped by the context in which it is delivered, as the planned intervention and context are usually inter-related and reciprocally interacting (Greenhalgh and Papoutsis, 2018). While impact, implementation and context are inextricably linked, very few studies have reported on these key aspects (Pfadenhauer, 2017). Hence, a primary objective of this overall programme evaluation was to describe the PDS interventions delivered, processes around their delivery, and the context within which they were delivered. This is necessary for understanding what happened in practice, and for identifying what is needed to support implementation and pinpointing areas for improvement.

Assessing the impact of PDS interventions for the person with dementia and their family members is also important and another primary objective of the evaluation. A key issue at the outset of this evaluation was how impact would be measured, and much consideration was given to outcomes and outcome measures. With regard to outcomes that are conventionally used in the types of effectiveness studies referred to above, the focus tends to be on measurable improvements in, for example, cognitive function, quality of life or behaviour, using standardized measures such as MMSE, QOL-AD or NPI. Given the practical implementation focus of this evaluation, it was deemed to be neither feasible nor worthwhile in this evaluation to adopt standardised measures or investigate changes in key outcomes for people with dementia and family carers participating in the PDS interventions. Such measures place a considerable burden on intervention participants (people with dementia and their family carers) but also on intervention providers who are busy delivering the new interventions. Furthermore, due to the nature of the PDS Grant Scheme, the timeframe of the evaluation was short, with intervention implementation taking place over a longer term than the evaluation process.

However, it was important to get feedback from people with dementia who, as intervention participants, are in a position to offer unique and valuable feedback on how the PDS Grant Scheme has impacted on them. Instead of using standardised outcomes measures in this evaluation, people with dementia and family carers participating in the interventions were asked to complete a short evaluation form at the end of the intervention, to assess the subjective impact of the PDS interventions. The evaluation forms focused mainly on wellbeing and emerging outcomes (i.e. things that happen as a result of unfolding events).

Given that impact, implementation and context are inextricably linked, we applied the Context and Implementation of Complex Interventions (CICI) Framework, a conceptual framework that addresses context, implementation and setting in an integrated way. It aims at simplifying and structuring complexity in order to advance our understanding of whether and how interventions work (Pfadenhauer, 2017).

### 3.2 Research design

The evaluation was designed with two core components: a process evaluation and an impact evaluation, both of which are described in more detail below. The development of both the process and impact evaluations were informed by the MRC guidance (Craig et al., 2008; Moore et al., 2015). The evaluation framework was refined in collaboration with the National Dementia Office (NDO) and following consultation with staff delivering PDS interventions in the 18 sites funded by the PDS Grant Scheme at two meetings.

#### 3.2.1 Process evaluation

Post-diagnostic support interventions are highly complex interventions implemented in complex health and social care systems. The overall PDS Grant scheme being evaluated in this study was even more complex because of the variation between and within intervention types, and among intervention participants. PDS interventions, even when based on pre-existing interventions that have been rigorously researched, are rarely fixed. The dynamic and emergent nature of the NDO's PDS Grant Scheme was apparent from early on, as many of the projects planned to implement their interventions using an iterative approach, allowing for the interventions to be adapted and tailored to the 18 different contexts and to meet different needs.

For this reason, the process evaluation was undertaken to provide an understanding of the workings of the PDS interventions at the 18 sites. For the process evaluation, a desk-based review of applications submitted by grantees to the NDO on the PDS interventions to be delivered was conducted, from which an initial description of the interventions was drawn up. Additional information about the interventions was gathered at two consultation and feedback meetings with grantees. Interviews were conducted with individual grantees and personnel involved in delivering the PDS interventions at the 18 sites to add to our understanding of the inner workings of the interventions implemented, and the experience of the project staff in doing so. The interviews took the form of semi-structured interviews, guided by a topic schedule, which was informed by the CICI framework (Pfadenhauer, 2018). Broadly, the themes covered in the interviews included:

- intervention development and adoption;
- intervention planning and delivery;
- project context; and
- staffing.

The extent to which the interventions are likely to become part of routine practice was also discussed in interviews.

With their consent, data on intervention participants was collected by the intervention providers as part of their routine service monitoring and evaluation. The researchers assisted in this process of data collection by developing a common client record form for use by personnel delivering PDS interventions. The purpose of this was to ensure that the data recorded by the projects was comprehensive, common across all 18 sites, and useful for informing a process evaluation. The client record form was refined in collaboration with the NDO and following consultation with staff in the 18 sites at two meetings. Data collected included socio-demographic and health-related information on persons with dementia, and socio-demographic

information on family carers participating in the PDS interventions. Attendance sheets were also developed to assist with the collection of process level data (e.g. participant attendance, access to intervention). Accordingly, a core dataset was collected for all persons with dementia and/or family members participating in the interventions delivered. Anonymised data from the client record form and attendance sheets were inputted by intervention staff into an excel workbook, developed for the evaluation. The workbook was developed so that it was simple and easy to use. An emphasis was placed on avoiding duplication and limiting the burden on those collecting the data as much as possible. A workshop was held to train the grantees/data collectors in the use of the excel workbook. A manual, prepared by the researchers, was available to the projects to guide data collection. In addition, the researchers were available to support and guide data collectors during the evaluation.

Anonymised data collected between January and June 2019 was made available by 17 sites<sup>2</sup> and was imported into SPSS for analysis, which mainly involved descriptive statistics to summarise the data, so as to describe the characteristics of people with dementia and their family members availing of the different PDS intervention types, and their intervention use and access.

### 3.2.2 Impact evaluation

In addition to the client record form, a short evaluation form was developed to assess the impact of the interventions on people with dementia and their family carers. The broad focus of the evaluation form was on wellbeing of participants. The wellbeing of people with dementia and their family carers is a central concern of the NDS. In the first information session with PDS grantees, wellbeing, or at least components of wellbeing, cropped up several times as an area of interest. This was echoed in follow-up telephone discussions with grantees. Moreover, enhancing wellbeing has been identified by people with dementia from across Europe as an important aspect of psychosocial interventions (Øksnebjerg et al., 2018). It has been argued that for an extensive programme of post-diagnostic support to be justified changes in cognition need to be accompanied by other changes such as wellbeing (Woods, 2006; Woods et al., 2012).

There is an extensive literature on wellbeing (Kennedy, 2013), but there is no single definition or understanding of wellbeing (NEF, 20). The capabilities approach to wellbeing draws on the work of Aristotle and relates it to the concept of human flourishing and the idea of realising one's true potential. It is referred to as the eudaimonic understanding of well-being and in practice is measured by asking questions about autonomy, self-determination, interest and engagement, aspirations and motivation, and whether people have a sense of meaning, direction and purpose in life (NESF, 2009).

There are many different frameworks or models of wellbeing. For this evaluation, the Eden Alternative Domains of Wellbeing were used as a framework to support the development of a set of questions for use as indicators in evaluating the PDS interventions. The Eden Alternative describes seven primary domains of wellbeing as:

- identity;
- growth;
- autonomy;
- security;
- connectedness;
- meaning; and
- joy.

<sup>2</sup>Although 18 applicants were awarded funded under the PDS Grant Scheme, one project had to withdraw due to obstacles encountered with regard to staff recruitment.

These seven domains can serve as a simple framework for asking thoughtful questions, including the development of questions for use in evaluating interventions (Eden Alternative, 2012). This approach was used in conjunction with the findings from qualitative studies with people with dementia, family carers and staff on their experiences and views of psychosocial interventions (e.g. Spector et al., 2011; Murray et al., 2016; Olsen et al., 2015).

The development of the evaluation forms was also informed by Public Patient Involvement (PPI) with people with dementia and carers at the developmental stage. This involved a meeting with a group of people participating in one of the PDS interventions to get their input into an evaluation form on wellbeing designed to capture the impact of the PDS intervention. Six people with dementia, two family carers, two staff members who knew the participants well, and two researchers attended the meeting. At the meeting, the researchers explained the purpose of the meeting, and gave a brief explanation of well-being and the seven domains in the wellbeing framework. For each of the seven domains, a set of statements were presented and the participants were asked to give feedback. This part of the meeting was facilitated by staff members. Participants gave their feedback by indicating whether or not they liked the statements, commenting on the appropriate number of statements, and choosing which statements they would like to see included in the evaluation form. They also made suggestions regarding the wording of statements. The evaluation forms were revised on the basis of further feedback from people with dementia and family carers, and were further refined following consultation with the NDO and grantees at a later date.

Because of the differences between the three intervention types, a separate evaluation form was developed for each intervention type, with modifications for groups or individual interventions, as relevant. The evaluation form had 19 questions, six of which were common across all three intervention types. An open-ended question inviting respondents to add anything else they would like to say about the intervention was also included on the form. The evaluation forms were designed to minimise the data collection burden for people with dementia and their family carers.

People with dementia participating in CST, CR and PE interventions were invited by intervention providers to complete an evaluation form. Some of the evaluation forms were self-administered by people with dementia, whilst other people with dementia needed support to complete the form. This support was provided by personnel delivering the interventions or family members. The authors acknowledge that this approach has the potential to introduce information bias, particularly social desirability bias (Visser et al, 1989). However, allowing health and social care professionals to support the person with dementia, where needed, is one way of enabling people with dementia to have their views included, albeit indirectly (Dewing, 2008). In addition, it is less demanding on persons with dementia and more practical and cost effective than bringing in external researchers to support people with dementia to complete the evaluation form, especially since the grantees were spread across the country.

Family carers participating in the PE interventions were also invited to complete an evaluation form. Responses to the evaluation forms were recorded anonymously in the PDS workbook, and with consent from the respondents, these were made available to the researchers for analysis.

### **3.3 Ethical approval**

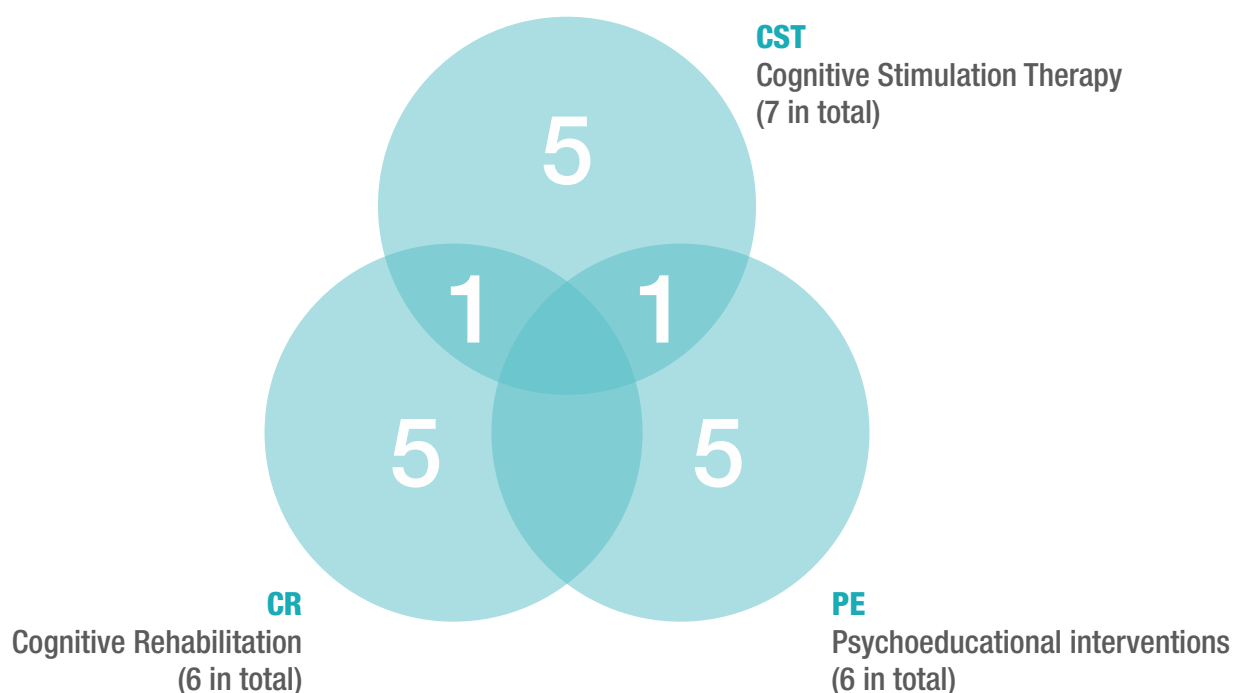
Ethical approval for the evaluation was granted by the NUIG Research Ethics Committee in December 2018.

## 4. The PDS Grant Scheme - Process evaluation findings

Under the PDS Grant Scheme, and following an open competition, a total of 18 projects (two in each CHO area) were awarded funding by the NDO of up to €25,000 to cover staff costs to deliver at least one type of PDS intervention to people with dementia and/or their family carers over an 18-month period commencing September 2018. One of the projects subsequently encountered obstacles when recruiting staff to deliver a CR intervention and withdrew from the programme. Accordingly, between January and June 2019, the evaluation's data collection period, 17 projects were implementing PDS interventions.

Fifteen of the projects focused on implementing one type of PDS intervention, five of which were implementing CST, five CR and five a PE intervention. A further three projects planned to deliver two types of PDS interventions, one CST and CR, one CST and a PE intervention, and one a CR and a PE intervention. Because of recruitment difficulties, the latter project opted to focus their attention on the CR intervention only during the data collection period, but later went on to deliver the PE intervention (Diagram 1). Therefore, this evaluation findings covers 19 PDS interventions in total, implemented by 17 projects. It is important to emphasise that the NDO did not prescribe which type of CST, CR or PE intervention that the grantees should deliver as part of the PDS grant scheme. Rather, the grantees could freely choose the type of intervention that they wished to implement. This approach was taken by the NDO to explore the feasibility of implementing different intervention types, finding out what works in different settings and what can be delivered within varying local contexts.

**Diagram 1: PDS intervention types planned by 17 projects**



Ireland's health and social care system is highly complex. Implementing post-diagnostic supports requires the involvement of a wide range of health and social care professionals working across acute hospital, community and home-based settings and across public and voluntary sectors. Reflecting this diversity, the projects funded under the PDS Grant Scheme were led by staff in a range of service provider organisations. The vast majority were based in the HSE, but the lead organisations were from different divisions of the HSE. HSE staff leading projects delivering CST interventions were working in primary care psychology, community mental health, community care and memory clinic services, and in an acute hospital and a community hospital. Two projects delivering CST interventions were led by a voluntary sector organisation. The projects funded to implement CR interventions were led by staff working in primary care OT services, hospital-based OT Departments, a community hospital and a HSE-funded dementia service. Those funded to implement PE interventions were based in primary care, community mental health services, a day hospital, and a hospital-based memory service. A voluntary sector organisation led one of the projects delivering PE interventions (details in Tables 1-3). The diversity of service providers achieved through the open competition helps to inform our understanding of the role and contribution to PDS of different facets of Ireland's complex health and social care system, which is valuable for the design of optimal post-diagnostic support.

The rest of this section focuses on the people in these services that were awarded grant funding and how they used the funding to implement these 17 projects. It also focuses on the interventions. Taking each of the three intervention types separately, it examines the interventions that the projects actually adopted or developed, and the adaptations that they made to them. It looks at their utilisation of intervention training where relevant, and the materials and resources needed to run the interventions. It then examines staffing and staff competencies needed to deliver the PDS interventions. It also examines the venues in which the interventions were held.

#### **4.1 The adopters - motivation for and use of grant funds**

As part of the PDS Pathways Project, a scoping exercise was undertaken to assess the current delivery of PDS interventions across Ireland and to identify service gaps. Through this process, it became apparent that in many areas there was a desire and motivation among services to deliver PDS interventions but without a dedicated resource it was not possible to undertake this work or introduce new interventions. This point was reiterated during the evaluation. Grant applications and interviews with grantees revealed that before funding had become available, many of the successful applicants had already recognised the need for post-diagnostic support for people with dementia and had already begun the search for solutions to address this support gap. With regard to CST, some applicants had previously been involved in delivering this intervention or had undertaken CST training and had wanted to implement the intervention in their own service, which the grant would allow them to do so. One applicant had previously commenced delivering CST and wanted to use the funding to enable continuation of the intervention and at the same time develop a CR intervention. Other projects funded to implement CR had either identified or developed and piloted a CR intervention prior to the PDS programme grant funding to fill a support gap that had previously been identified. Due to resource constraints, for most of these early adopters it had not been possible to offer the intervention at all or only on an ad hoc and sporadic basis. These services sought funding to establish the intervention in their area or put it on a formal footing and offer it on a more regular basis.

A motivation for the development of PE interventions stemmed largely from applicants' recognition that after diagnosis most people with dementia do not get to meet a health professional to discuss their diagnosis and the implications of this for them, or at best have one such meeting. They wanted to implement an intervention that would take place over four to six weeks to cover a range of information and educational needs and help address issues that people with dementia and their family carers have following a diagnosis. Some projects had



been providing psychoeducation informally to people after a diagnosis of dementia. For example, the motivation of one Community Mental Health Team was to carry out the psychoeducational work that they had been doing during their routine visits to people with dementia, but to do this in a planned, structured and systematic way.

The funding from the PDS Grant Scheme was intended to secure dedicated time for staff to implement PDS interventions. It could only be used for staffing, either to directly fund staff already in post, provide backfill to cover an existing staff member, or recruit a new staff member not currently in post. The Project Leads took different approaches to using the funding. An approach that worked well in one project was the use of the funds by a service manager to free up a senior health professional already in position to plan and deliver the CST groups. The health professional was highly experienced and skilled, both in dementia and developing and implementing psychosocial interventions for people with dementia, and had completed CST training in the UK. The service manager, working closely with the senior health professional, oversaw the process of implementation, and took an active role in the planning and implementation including working as a CST group co-facilitator. A similar approach was used in another two projects which set out to deliver CR interventions. A senior member of staff was identified internally within the service to implement the intervention and the funding used to backfill the post of this person. Again, the health professionals were supervised by the service manager who oversaw the process of implementation and took an active role in the planning and implementation. Most of the projects implementing PE interventions also took this approach. One project encountered difficulties with recruitment of a new staff member and instead used the funding to extend the number of days worked per week by a senior health professional to implement both a CR and a PE intervention.

A second approach that worked well was the use of funding to backfill the post of a senior health professional leading the project who went on to involve and lead a small team of trained CST group facilitators at assistant therapy level. This approach worked well because there were trained CST group facilitators already in place for senior staff to involve and who were co-located in the same service. With dedicated time, this same senior health professional was also able to deliver a CR intervention.

A third approach, taken by four projects implementing CST and/or PE interventions, was for one senior health professional, or two working together, to lead and co-ordinate the project and use the funding to recruit new staff usually an assistant psychologist or therapy assistant. A difficulty with this approach was the time taken to recruit new staff. All projects using this approach experienced delays in recruitment, describing it as a huge challenge, with lots of obstacles to overcome. The delays had significant knock-on effects. For example, Project Leads had to invest time in administration tasks that could have been easily managed by an assistant, or learn skills that were no longer used once the assistant was in post, thus diverting their valuable time away from other important work. Delays in recruitment also led to delays in intervention development/adaptation and commencement of programme delivery. When the assistant was in post, CST and PE interventions were only successful when the lead(s) remained closely involved and engaged in the process of intervention development, planning, implementation and delivery, and assistants received training, and ongoing support and supervision from senior health professionals. It also helped if newly recruited staff had prior clinical experience of dementia and knowledge of the HSE and the wider health system and how it worked. While this approach has built important capacity within the system for PDS interventions, it does require additional time from senior professionals to support and supervise these staff.

Two primary care-based projects planned to recruit a new staff member to the service who would work with the Project Lead to implement a CR intervention that had already been developed and piloted. Neither of the projects, however, could get approval from Human Resources to recruit new staff. One of the projects managed to develop and deliver the CR intervention using existing staff resources (i.e. the Project Lead, a Senior OT, working together with another Senior OT on the primary care team). This was made possible by a supportive OT

manager. It involved diverting the OT staff from some of their daily work and allocating part of their caseload to other primary care staff. Throughout the project, the project staff managed and juggled the demands of their daily work and the implementation of a new intervention, but found this challenging and also had to contend with the possibility that intervention delivery could be interrupted at any time if caseloads became unmanageable.

Finally, one organisation leading two of the projects had trained day care centre staff to deliver CST prior to grant funding. This suggested that the organisation had a cohort of dedicated and trained staff ready to deliver CST, but it turned out that the capacity and skill level of staff to deliver CST had been overestimated. Identifying and recruiting experienced and skilled group facilitators proved to be a significant challenge for this organisation, and is likely to be a major ongoing challenge in the future.

Further issues relating to staffing and staff competencies are addressed in Section 4.3.

## 4.2 The Interventions

### 4.2.1 CST interventions

#### *Intervention adoption and adaptation*

Seven projects in the NDO's PDS Grant Scheme adopted CST interventions. A total of 89 people with dementia participated in the CST interventions over the data collection period (see Section 5). The UCL Making a Difference CST Programme figured strongly among these projects. It was adopted by six projects, and CogsClub, an offshoot if it, was adopted by the remaining project (Table 1). Although CST can be provided on an individual basis, all seven projects delivered their CST intervention as a group intervention, with the maximum size of the group between seven and ten people with dementia. None of the projects offered maintenance CST. CST was mainly offered by the projects to people living in the community, including those attending day care, but one project focused on CST for in-patients in an acute hospital.

An advantage of CST is that it is adaptable to different cultures and contexts and all of the NDO funded projects made some adaptations to the CST intervention including changes to the structure of the intervention (Table 1). CST is generally provided using a closed format and the majority (5/7) of the CST interventions were closed, i.e. the intervention ran for a set period of time and all intervention participants were admitted at the same time with no new people joining the group after the first week. Originally designed as a closed group format, The Making a Difference CST programme typically has a total of 14 themed sessions, each lasting for one hour, usually delivered twice weekly over seven weeks. However, it is not unusual for the format of the intervention to be changed in response to time constraints, resources limitations and/or to meet participant availability and accommodate access. In the NDO's PDS Grant Scheme, the CST sessions lasted between 45 minutes and two hours. Three of the projects implementing closed group interventions offered CST as a 14-session intervention, two of which delivered the intervention over seven weeks (i.e. a two-hour session for seven weeks), and one over 14 weeks. These changes were made to make it easier for participants to travel and attend the sessions, accommodate carer commitments, and for staff logistical reasons. However, two projects dropped sessions from the intervention to deliver eight one-hour sessions, which would allow for the intervention to be delivered a greater number of times in a given year. This decision was also influenced by concerns that people with dementia, especially those with advanced dementia, may become bored with the sessions over time.

Table 1: Key Dimensions of Cognitive Stimulation Therapy Interventions

	Project 03	Project 04	Project 05	Project 06	Project 08	Project 11	Project 18
<b>CST intervention adopted</b>	UCL Making a Difference CST Programme	UCL Making a Difference CST Programme	UCL Making a Difference CST Programme	UCL Making a Difference CST Programme	UCL Making a Difference In-patient CST Programme	UCL Making a Difference CST Programme	Cogs Club (developed by Jackie Turpin)
<b>Group / Individual</b>	Group	Group	Group	Group	Group	Group	Group
<b>Open / Closed Group</b>	Closed	Closed	Closed	Closed	Open	Closed	Open
<b>No. of weeks / sessions</b>	8 weeks / 8 themed sessions	8 weeks / 8 themed sessions	7 weeks / 14 themed sessions	7 weeks / 14 themed sessions	13 themed sessions delivered on a rotational basis	14 weeks / 14 themed sessions	Themed sessions delivered on a rotational basis
<b>Participants</b>	People with dementia living in the community	People with dementia living in the community	People with dementia living in the community	People with dementia living in the community	People with dementia on acute hospital wards	People with dementia living in the community	People with dementia living in the community
<b>No. of places per group</b>	8-10	8-10	4-7	Up to 10	Up to 10	6-7	Up to 10
<b>Location</b>	Day Care Centre	Family Resource Centre	Community Nursing Unit	Public library	Acute Hospital	Acute Hospital / Community Hospital / District Hospital	Community Hospital
<b>Service Provider</b>	Alzheimer Association	Alzheimer Association	Psychiatry of Later Life / Care of Older People	Primary Care Psychology Service	Acute Hospital (OT and S&LT Dept)	Memory Clinic	Community Hospital

The in-patient CST intervention used an open group format, i.e. people could leave and join the group on a regular basis. This was necessary because people with dementia were being admitted to and discharged from the hospital wards at different times and had varying lengths of stay in hospital. The CogsClub intervention also operated on an open basis, which meant that participants were not discharged from the intervention, but could attend for as long as they could benefit from cognitive stimulation.

Changes were also made by projects within thematic sessions. For example, some of the projects stopped using the theme song or catch with a soft ball for introductions as they found that physical games did not seem to work well with the group, or perhaps were not suited to an Irish context. Health professionals in one project emphasised that while changes were made to thematic sessions, the CST principles were strictly adhered to. Grantees also spoke about tailoring sessions to the needs of the group or individuals within the group to take account of, for example, communication difficulties or educational levels of participants.

The consensus among grantees was that at least two experienced group facilitators are needed to run the CST sessions and they stressed the importance of staff being experienced and skilled at facilitating group work for people with dementia.

### **CST training**

CST training has been identified as important for supporting the implementation of CST in practice and this was discussed in interviews with grantees. A senior health professional in one project who had travelled to the UK to avail of the CST training identified this as being very helpful for planning the intervention. Generally, however, the CST training day in the UK is not easy to access for health professionals based in Ireland. Many of the NDO-funded projects and group facilitators were using the CST training manual and DVD, which is available at a small cost, to guide practical delivery and implementation of the CST intervention. The use of the training manual and DVD worked well for senior health professionals with prior experience of delivering CST or other psychosocial interventions, and for assistants with no prior experience but who received close supervision from and co-facilitated the groups with senior health professionals. Even with close supervision, some less experienced staff felt that it would be of value to take part in interactive CST training. Exchange visits with or mentoring by other projects delivering CST were also put forward as ways of learning more about CST and addressing challenges associated with its implementation.

As mentioned earlier, one organisation arranged for the delivery of a one-day workshop on CST to day care centre staff across the country who had expressed an interest in delivering CST. The training was provided by an experienced CST trainer. However, despite receiving CST training, the staff lacked the experience, skills and confidence to run or facilitate CST groups. In addition, the delivery of the intervention required staff to be flexible and deliver the programme outside of their usual place and time of work but staff were either unwilling or unable to do this. As well as delivering their CST intervention, another project provided CST training to a group of health professionals with a view to spreading the provision of CST in the area. It was expected that following training these health professionals would go on to lead and facilitate their own CST groups. While CST training was provided to 21 health professionals, few actively sought to deliver the intervention after training. Thus, staff readiness and flexibility as well as support from management are important factors when planning CST training in order to scale up CST implementation.

### **Materials and resources**

Materials are needed for running CST sessions, and the grantees described collating packs covering up to 14 themes, with materials (e.g. visual images, artefacts, props) required for each. They spoke about the large amount of time invested in sourcing and building up a bank of suitable, culturally and locally relevant materials. They reported that it could be difficult to source suitable materials and props (e.g. skipping ropes from 'olden days'), but over time access to materials grows and a resource bank builds up. For example, staff in an acute hospital discovered that the hospital keeps an archive of photographs from the local area, which they were able to access and use to prompt discussions. While some grantees were aware from the outset of what was involved in sourcing materials, others had greatly underestimated this. Some projects reported that some materials were costly, a cost that had not been factored into the budget.

## **4.2.2 CR interventions**

### **Intervention adoption and adaptation**

Six of the projects offered Cognitive Rehabilitation interventions (Table 2). A total of 80 people with dementia and 64 family carers participated in CR interventions over the data collection period (See Section 5). Among these projects, the type of CR that tended to prevail was memory rehabilitation. One of the projects adopted Home-based Memory Rehabilitation (HBMR), an OT-led memory rehabilitation intervention. The intervention was offered on an individual basis and delivered in the person's own home, as HBMR had originally been designed. Although CR is usually offered as an individual intervention (Kudlicka et al., 2019; Cahill, 2018), the remaining five projects used a group format, with small groups of between five and seven people with dementia. Two of these projects were strongly influenced by HBMR and

incorporated elements of it into their interventions, but adapted these for delivery in a group format. One project combined CR with a PE component, using elements of HBMR. Another project developed an intervention that can best be described as a hybrid model, incorporating both HBMR and another CR intervention called Jog Your Memory. The final intervention was Specialised Memory and Attention Rehabilitation Therapy Programme (SMART), a structured intervention developed for OTs by OT staff in a hospital-based OT Department. This intervention includes education about cognitive strengths and weaknesses, process training (which refers to the development of skills through direct retraining or practicing the underlying cognitive skills), strategy training (which involves the use of environmental, internal and external strategies) and functional activities training (the application of the other three components in everyday life).

While none of the projects adopted individual, goal-oriented CR, some projects tried to individualise the intervention by conducting individual home-based assessments prior to the group sessions. The assessments focused on goal setting and areas of interest, and the goals and areas identified were integrated into the group sessions.

CR is usually provided in 10 weekly sessions over three months and HBMR once-weekly over six weeks. In the NDO's PDS Grant Scheme, the format of the CR interventions varied. They ranged in length from four to seven weeks. Several of the interventions included pre- and post-assessments, and a follow-up appointment, conducted in some cases as home visits. In all projects, family members were encouraged to attend the CR sessions, but people with dementia were not excluded if a family member or friend could not attend with them, and some person with dementia chose to attend on their own. Unlike CST, CR groups were sometimes presented by one group facilitator.

**Table 2: Key Dimensions of Cognitive Rehabilitation Interventions**

	<b>Project 01</b>	<b>Project 07</b>	<b>Project 13</b>	<b>Project 16</b>	<b>Project 17</b>	<b>Project 18</b>
<b>Service provider</b>	HSE-funded dementia support service	Hospital-based OT Department	Primary care OT service	Hospital-based OT Department	Primary care OT service	Community Hospital
<b>CR Intervention adopted</b>	Memory Rehabilitation Group Programme  Developed by CMHT staff	SMART Programme,  Developed by OT department staff	Home-based Memory Rehabilitation (HBMR) Programme	Memory Rehabilitation and Carer Support Group Programme  Informed by OT Memory Rehabilitation programme	Coping Skills for Everyday Memory Loss Programme,  Informed by OT Memory Rehabilitation programme	Cognitive Rehabilitation Programme,  Informed by OT Memory Rehabilitation and Jog Your Memory Programme
<b>Participants</b>	People with dementia; family carers encouraged to attend	People with dementia; family carers encouraged to attend	People with dementia; family carers encouraged to attend	People with dementia; family carers encouraged to attend	People with dementia; family carers encouraged to attend	People with dementia; family carers encouraged to attend
<b>Location</b>	Memory Technology Library (Hospital campus)	Education and Training room, Hospital campus	Person's home	Memory Technology Resource Room (Hospital campus)	Memory Technology Resource Room; Primary Care Centre	Community Hospital / Person's home
<b>Group / Individual intervention</b>	Group	Group	Individual	Group	Group	Group / Individual
<b>Open / Closed Group</b>	Closed	Closed	N/A	Closed	Closed	Closed
<b>No. of weeks / sessions</b>	6 weeks / 6 sessions	7 weeks / 7 sessions	4-5 weeks / 4-5 sessions	6 weeks / 6 sessions	6 weeks / 6 sessions	4-6 weeks / 4-6 sessions
<b>No. of places per group</b>	6 PwD + 6 FC	7 PwD + 7 FC	N/A	6 PwD + 6 FC	5 PwD + 5 FC	6 PwD + 6 FC

### **CR training**

With respect to CR training, many of the staff delivering the CR interventions had attended one of the four Cognitive Rehabilitation Therapy Master Classes that had been organised by the NDO, and facilitated by OT, Mary McGrath, and this was identified by grantees as being extremely helpful. In addition to this training, the project offering HBMR linked in directly with Mary McGrath to get a better understanding of how the intervention operates in practice. Other projects also linked in with Mary McGrath or other locally based OTs, who offered advice and assistance with the development of their intervention. Some grantees were also using the CR manual devised by TCD and the ASI (Kelly and O'Sullivan, 2015). Generally, less experienced staff such as assistant psychologists or OT assistants, recruited to deliver CR, were supervised by an experienced staff member.

Training needs identified by staff delivering CR included training to understand memory and cognition (e.g. Harrison training in cognition) and training to become a skilled communicator. Staff delivering the projects identified the need for ongoing continuing professional development (CPD) to ensure that they were kept up to date with developments in the field more broadly and specifically in relation to psychosocial interventions.

### **Materials and resources**

Assistive technology or memory aids can be used to augment CR interventions and improve uptake of the strategies. HBMR has a particular set of memory aids associated with it including a whiteboard, orientation clock, calendar and a diary or memory book, each of which can be purchased at a small cost. Many of the projects were using these as part of their CR intervention. There were small printing costs associated with other resources such as prompt cards, customised medication checklists and safety checklists. Funding from the NDO could not be used to purchase assistive technology and access to memory aids was variable across the projects delivering CR. Some had sourced additional funding to purchase equipment, allowing them to give the memory aids free of charge to everyone participating in the intervention. Others because of financial constraints could not do this. However, through their association with the Memory Technology Resource Rooms, it was possible to loan equipment e.g. orientation clocks, to people with dementia for a trial period, allowing the person to test out the product and see how well it worked before deciding if they needed or wanted to buy it for themselves. Some questioned the necessity of giving every participant all of the memory aids, based on a concern that this may be redolent of 'a one size fits all' approach, and lead to memory aids being overprescribed rather than being tailored to the specific needs of individuals.

## **4.2.3 PE interventions**

### ***Intervention adoption and development***

A total of 63 people with dementia and 76 family carers participated in PE interventions over the data collection period (See Section 5).

Some grantees set out to develop a new PE intervention from scratch. For example, one project aimed to develop an intervention that would educate, support and enable a dementia diagnosis to be integrated into a person's life and occupational identity. Another project developed a new PE intervention for people recently diagnosed with young onset dementia. Developing PE interventions is a significant undertaking. It requires a high level of expertise. Furthermore, much time and resources are needed to develop new PE interventions. Not surprisingly, projects that started developing new PE intervention from scratch after the allocation of grant funding spent several months in the development phase. This was at the expense of intervention implementation and delivery, leading to long delays before intervention delivery could commence. For this reason, it was more difficult to assess the impact of PE interventions as part of the PDS grant scheme evaluation.

Some projects used the funding to implement PE interventions that they themselves had already developed or were in the process of finalising. For example, one grantee had already developed and evaluated a memory rehabilitation intervention with a PE component for people diagnosed when the condition was still at the mild stages. This intervention was not suited to people who received a diagnosis later in the disease and the project wanted to revise and develop it and make it suitable for this group. This involved paring back the memory rehabilitation component and bringing the PE component much more to the fore. As well as providing practical information, the PE intervention was designed to include topics such as connectedness, peer support and future care planning and decision-making. Another project had developed an individual PE intervention that focused primarily on the dyad (person with dementia and family), their relationship and the impact of a dementia diagnosis on the dyadic relationship, which the project team saw as a break from traditional PE interventions. While it covered key issues such as driving and legal issues, a core element of the intervention was assessing dyad readiness and facilitating the dyad to engage in conversations about these and other issues and about future care planning.

Among the projects implementing PE interventions, only one used the funding to formalise an existing training programme for family carers. This project also developed a new PE intervention for people with dementia.

In interviews, several of the projects referred to the DSIDC's Next Steps Guidance Document on Psychoeducational programmes (Gibb et al., 2019), developed as part of the PDS programme, highlighting it as an important and practical tool which filled a gap and helped them to develop their PE intervention and guide implementation.

**Table 3: Key Dimensions of Psychoeducational Interventions**

	PDS-02	PDS-06	PDS-09		PDS-12	PDS-14	PDS-15
<b>Service provider</b>	Primary Care Service	Primary Care Psychology Service	Alzheimer's Association		Day Hospital	Community Mental Health Team	Hospital-based Memory Service
<b>PE intervention adopted</b>	PE intervention 'Side by Side' developed by project	PE intervention developed by project	PE intervention for family carers based on ASI Family Carer Training Programme	PE intervention for individuals with dementia	PE intervention 'With Ourselves in Mind' developed by project	PE intervention developed by project	PE intervention developed by project
<b>Participants</b>	Dyads (people with dementia and family carers)	Dyads (People with dementia and family carers)	Family carers	People with dementia	Dyads (People with dementia and family carers)	Dyads (People with dementia and family carers)	Dyads (People with young onset dementia and family carers)
<b>Location</b>	Community Centre	Library	Family Resource Centres / Hotels	Person's home / Nursing home	Day hospital	Person's home	Hotel
<b>Group / Individual programme</b>	Group	Group	Group	Individual	Individual	Individual	Group
<b>No. of places per group</b>	6 PWD and 6 FCs	Up to 10 PwD and 10 FCs		N/A	N/A	N/A	6-8 PwD and 6-8 FCs
<b>Open / Closed Group</b>	Closed	Closed	Open 5 weeks / 5 sessions	N/A	N/A	N/A	Closed
<b>No. of weeks / sessions</b>	6 weeks / 6 sessions	6 weeks / 6 sessions		5 weeks / 5 sessions	4 weeks / 4 sessions	6 weeks / 6 sessions	4 weeks / 4 sessions

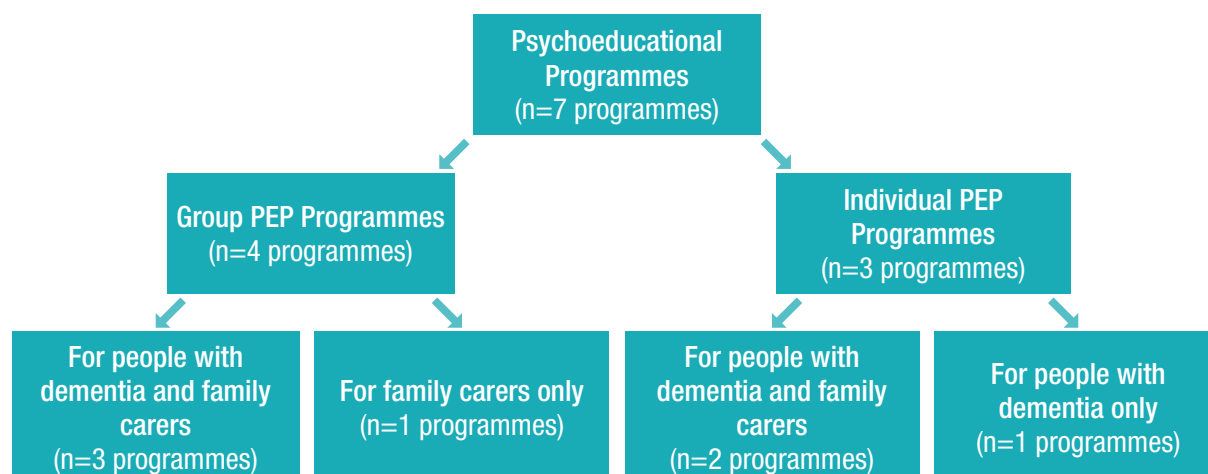
### PE intervention implemented

There was huge variability among the seven PE interventions implemented, each being quite different from the others. All of the PE interventions included an education component, but the educational content covered varied hugely. The extent to which the interventions supported participants to manage circumstances related to dementia such as emotional response or stress also varied hugely. Although one of the benefits of psychoeducation is that it is flexible as a model (Lukens and McFarlane, 2004), the structure and the contents of the PE interventions implemented under the PDS Grant Scheme varied so much that a more detailed evaluation of the interventions would be needed to provide an accurate description of the interventions, including the educational content covered, the underpinning psychological theories and expected outcomes, and to tease out which PE interventions worked well in which circumstances, and for whom.

As well as differences in content and approach, the target beneficiaries, mode of delivery and settings also varied. Four were group interventions. Three of these were dyadic interventions (with both person with dementia and family member participating), accommodating between 6 and 10 people with dementia with 6 and 10 family carers in the group, and all used a closed group format. One was a group intervention for family carers only which operated as an open group. All four group interventions were delivered outside of a healthcare setting, in libraries, hotels, family resources centres and community centres.

Three of the PE interventions were individual interventions. Two of these were dyadic, one of which was delivered in a day hospital, and the other in the homes of the beneficiaries. Both interventions were able to respond to complex issues such as alcohol related problems, pre-existing mental health problems, personality disorders, lack of insight or poor acceptance of services. These issues are likely to be more difficult, and perhaps inappropriate, to address, in a group setting. The home-based intervention has been chosen based on past experience in the area of running group-based interventions (e.g. CST, Carers Groups, Alzheimer Cafes), which had not attracted many people and were discontinued. The project is located in a large county, where most people live in rural areas and find it difficult to get to the group because of long travel distances and poor transport networks. High levels of stigma associated with dementia, non-acceptance of diagnosis and a desire to remain private also contributed to people's reluctance to take part in group activities. Interestingly, stigma was cited by many of the projects delivering group dyadic PE interventions as a barrier to recruitment. The other individual PE intervention was targeted at people with dementia only and was generally provided to people with dementia in their own homes, but could be provided to people with dementia in a nursing home where this was their place of residence. This project, also based in a large county with large rural areas, had intended running the PE intervention for people with dementia using a group format, but found that people were not comfortable with this, and thus changed it to a home-based intervention.

**Diagram 2: Psychoeducational interventions by format and target beneficiary group**



*The length of the PE interventions varied from between four to six sessions, delivered over four to six weeks (Diagram 3).*



### 4.3 Staffing and staff competencies

Across the 17 project sites, staff involved in implementing and delivering CST interventions came from a range of disciplinary backgrounds. In the projects delivering CST, these included nurses, psychologists, OTs and Speech & Language Therapists working at a senior level and assistant psychologists and OT assistants. The majority of staff delivering the CR interventions on the PDS programme were OTs, with nurses and social workers also involved in one project. Research in Canada has found that, of the cognitive interventions, CR is the one most commonly offered by OTs, which may be explained by the fact that CR is closely related to the OT profession's core concepts of person-centred approaches and maximising occupational performance (Robert, Gélinas and Mazer, 2010). OTs interviewed stressed the importance of OT involvement in CR interventions, with some stating that it was essential. However, staff delivering cognitive rehabilitation may be drawn from a number of professional backgrounds, such as clinical psychology, occupational therapy or nursing (Kudlicka et al., 2019). Staff delivering PE interventions came from a range of disciplinary backgrounds including nurses, psychologists, OTs and social workers. Few of the projects took an interdisciplinary approach to the delivery of the intervention sessions. However, staff on one project delivering a CR intervention, which involved a nurse, OT and social worker, highlighted the value of an interdisciplinary approach, as it allowed for different information and perspectives to be offered to people with dementia. Two other projects also took an interdisciplinary approach to the delivery of their interventions.

What we found was that successful implementation of PDS interventions did not so much depend on the disciplinary backgrounds of staff, but on the motivation, experience and skills of staff and on the characteristics of the 'team' implementing the interventions. All three elements are important and should not always be assumed to co-exist.

Across all three intervention types, the interviewees also highlighted the importance of staff having knowledge of dementia (ideally from diagnosis to end of life), training in dementia care, and experience of working with people with dementia across all stages of the condition.

The interviewees stressed the importance of staff having experience of, and the skills and abilities for planning and implementing psychosocial interventions. The most successful projects were those which engaged health professionals who had 'know-how, i.e. they were knowledgeable about the interventions, the resources needed and the implementation challenges involved; they were experienced at planning, developing and implementing psychosocial interventions; they were highly adept at the logistical organisation and planning; and they had the necessary skills to build relationships and to 'connect into' the parts of the system from where they were seeking referrals. This is an integral part of the work of intervention implementation.

Across all group interventions, grantees stressed the importance of staff being experienced and skilled at facilitating group work for people with dementia. For CST, group facilitators need to be person-centred, skilled in group communication, which is inherently creative, have good listening skills, and be open and mindful. They need to be flexible, creative and able to present the sessions in a fun, positive and stimulating way. They need to be able to lead the group and keep to the overall theme, whilst at the same time, allowing and facilitating people to speak and take the discussion in a direction that is meaningful to them, without one person dominating the discussion. They need to be able to facilitate discussion of complex and challenging issues and respond to questions such as accepting a dementia diagnosis, stigma associated with dementia, progressive nature of the condition, and end of life in a sensitive but transparent way. They need to be able to orient people in the group sensitively when appropriate, and be aware of the background and circumstances of different individuals in the group, e.g. traumatic background, poor literacy. For example, health professionals providing CST to in-patients with dementia, almost half of whom had primary education or less, noticed that literacy levels of participants were low and adjusted the sessions accordingly. Given the nature of dementia, the difficulties that people with dementia might experience (e.g. way-finding, repetition) and that each person is individual, it was stressed that group facilitators need to be willing to continually

plan and anticipate what might happen, have the ability to adapt quickly, and be skilled at finding solutions to the everyday practical problems that inevitably arise. This all requires skill. There also needed to be good rapport between staff when sessions are jointly facilitated.

While CR is a different intervention to CST, CR group facilitators need to be equally experienced and have many of the same group facilitation skills. Additional skills related to goal setting, and being able to provide positive but realistic feedback to people recently diagnosed with dementia. The importance of good facilitation skills for the implementation of PE interventions has been highlighted by Cheston et al. 2018.

The project teams directly implementing PDS interventions were generally small teams, often made up of only two or three people, other times they comprised slightly larger numbers. The teams were configured in slightly different ways. They could be led by a service manager or senior health professional and there were advantages of having two senior health professionals working together to implement the programme. But it was not just the experience and skills of the staff that was important; how the handful of people on the 'teams' delivering the interventions worked together was hugely important for successful implementation. Successful teams were highly motivated, well organised and tightknit. Teamwork and excellent working relationships, especially trusting and mutually supportive relationships, among staff on the project team who got along well was extremely important for the interventions to be successfully implemented and embedded. Where junior or less experienced staff were engaged on these teams, they needed to work closely with project leads and senior staff, and receive high levels of supervision and support.

While the teams implementing the PDS interventions were made up of a handful of people, these teams needed to work with a wide range of stakeholders within their own organisations as well as people outside of their organisation to ensure success. The teams had to share and make known to others what they were doing, get support from others, which in practice required adaptability. This could include management agreeing to support the project by, for example, facilitating project leads to divert some of their time to working on the project. It could include staff in and outside the organisation becoming aware of and knowledgeable about the intervention, and agreeing to support the intervention. For example, a doctor asked to support the project must be willing and have time to assess the suitability of people with dementia for an intervention, discuss it with them and refer them on to the intervention where appropriate. Or a hospital porter asked to support the team must be willing to be vigilant and act as a support to people with dementia trying to find their way to and from the intervention. Thus, the connectedness and relationships of the teams to other staff is of utmost importance, as is the willingness of other staff to adapt and contribute. Good standing and reputation of health professionals within and outside their organisation was also a facilitating factor.

#### 4.4 Venues

Interventions were delivered by the projects in a wide range of venues. CST interventions were delivered in a public library, a family resource centre, a day care centre, and rooms made available to the projects in acute, community and district hospitals and a community nursing unit (Table 1). Venues used for the delivery of CR groups included Memory Technology Resource Rooms, rooms in a primary care centre and a community hospital. One group was held in an education and training room, based in an acute hospital.

Some of the projects had rooms readily available to them. However, many projects started off with no room and while finding rooms for use was described as challenging and time-consuming, persistence usually paid off. Serendipity sometimes played a part. The ability to use rooms in HSE buildings was regarded as a great resource. Grantees reported that delivering an intervention in a new venue could be challenging as it required facilitators to deliver a group in a new environment. This could put facilitators outside of their comfort zone, as it is hard to anticipate what might go wrong (e.g. IT, access to and circulation within the building, parking

etc.). However, the rooms acquired often worked out better than anticipated. One project sourced a room in three different HSE buildings so that the CST intervention could be provided to people with dementia in three different areas of the county, thus reducing the distance that participants had to travel to access the intervention.

Many of the rooms including MTRRs, in which the CR, CST and PE interventions groups were held, were located on hospital grounds. Grantees reported that participants seemed to like the hospital setting. They suggested that people with dementia and family carers were more amenable to attending a PDS intervention when held in a hospital setting, and surmised that this was because the hospital setting encouraged people to view the intervention as a therapeutic or rehabilitative intervention prescribed by a health professional on medical grounds. This, they believed, gave the intervention more credibility than an intervention held in a non-medical community setting where it would more likely be viewed as a social activity without therapeutic or rehabilitative benefits. It may also have played a role in downplaying stigma as participants could have been going to the hospital for any reason and were able to share the fact of a 'hospital appointment' with others. Grantees that delivered CST in non-medical settings reported that participants liked the venue. However, take-up of interventions in non-medical settings tended to be low and, although it seems counter-intuitive, there is a possibility that the venue was a contributing factor.

For the in-patient CST intervention, the allocation of a room in the hospital to hold the CST session made it possible to run the intervention, but there were major constraints with the room. The hospital has no dedicated room for providing psychosocial interventions to in-patients and the allocated room was far from ideal for running the sessions. The room was noisy because of building works and drilling. It is a multi-purpose room, which is used for staff breaks, staff meetings and for other groups and purposes. Consequently, the time allocated for the sessions was limited. This placed pressure on the staff getting patients to and from the room, which was already logistically challenging and time-consuming, as each patient needed to be accompanied and three staff are needed to get patients ready (out of bed, to the toilet, wheelchairs) and bring them to the group and back to the ward. Because the room had to be vacated immediately after the session, there was no opportunity for tea and coffee to facilitate social interaction after the session. Participants seemed to have no complaint about the room, but there is a context to this as people with dementia participating in the intervention were often medically well but waiting for transfer to another care setting. Waiting in a hospital bed can be extremely boring and any opportunity for stimulation and engagement is likely to be welcomed.

## 5. PDS Intervention participants

Data collection for the evaluation took place within a six-month period of the overall 18-month PDS Grant Scheme. The information about intervention participants presented in this section of the report is based on 232 people with dementia and 140 family carers of people with dementia who participated in the PDS interventions between 1 January and 30 June 2019 and for whom data was collected by the projects (Table 4). An additional 31 people with cognitive impairment also participated in interventions during this period but are not included in the analysis. People who had only commenced an intervention which was still in progress in late June 2019 are not included either.

**Table 4: Participation in PDS interventions January 2019 to June 2019**

	No. of people with dementia (all projects)	No. of family carers (all projects)
CST	89	n/a
CR	80	64
PE	63	76
<b>Total</b>	<b>232</b>	<b>140</b>

The participants reported on in this section are a subset of the total number of people who participated in the PDS interventions over the lifetime of the PDS Grant Scheme. The total number of people who participated in the PDS interventions between September 2018 and end of August 2019 is presented in Appendix A.

Between January and June 2019, a total of 89 people with dementia participated in the CST interventions delivered by six of the seven projects<sup>3</sup>. All 89 participated in group programmes. Family carers did not participate in any of the CST interventions (Table 4).

A total of 80 people with dementia took part in CR interventions. Family carers were encouraged to attend the CR programmes. Not everyone with dementia had a family member in attendance with them, but a total of 64 family carers attended the CR programmes with their relative with dementia (Table 4). CR programmes comprised both group and individual programmes; 63 people with dementia and 50 family carers participated in group programmes and 17 people with dementia and 14 family carers in individual programmes.

Participating in the PE interventions were 63 people with dementia and 76 family carers (Table 4). Participation in PE interventions is somewhat complicated, as there was a mixture of interventions targeted at family carers only, people with dementia only and dyadic programmes and a mixture of programmes using either group and individual formats (see Diagram 3). The majority of people with dementia (n=46) and family carers (n=46) participated in individual dyadic PE interventions. A much smaller number of people with dementia (n=7) and family carers (n=7) participated in group dyadic interventions. Twenty-three family carers participated in a group intervention for family carers only. Ten people with dementia participated in a PE intervention for people with dementia only, which were provided on an individual basis.

<sup>3</sup>One project (PDS-06) only commenced delivering its first CST programme to four people with dementia in the middle of June 2019 and these four people were not included in the analysis.

## 5.1 Characteristics of participants with dementia

The characteristics of people with dementia participating in each of the three intervention types are presented in Table 5. For each type of intervention, there were more women than men among the people with dementia participating. The ages of participants were wide-ranging. The vast majority of participants (>90%) were aged 65 years and over. While younger people with dementia in their 50s and early 60s participated, their numbers were small, and disproportionately concentrated in a PE intervention developed specifically for people with younger onset dementia.

With regard to educational level, overall approximately one in five participants with dementia had primary level education. Although this was relatively similar across each intervention type, there were variations among the projects, with some projects having comparatively higher proportions of participants with lower levels of education. In interviews, several of the project staff referred to this and how they had to tailor the intervention to the educational levels of participants, something which they had not anticipated before project commencement. However, one CR project located in a socially disadvantaged area noted higher than expected educational levels among their participants.

Across all intervention types, close to two-thirds of participants with dementia were married and more than half were living with their spouse or partner. A spouse or partner, followed by an adult child, was most frequently identified as the primary informal carer for people with dementia across all intervention types. Several participants, particularly those with mild dementia, were self-caring and did not see themselves as needing a family carer. This explains the relatively higher percentage of participants with no informal carer particularly on the CR interventions, but also on CST interventions. A small number of participants had no family member available to provide care and support to them.

The vast majority (>95%) of participants on the CR and PE interventions were living in their own homes. Since almost one quarter of participants on the CST interventions were in-patients in an acute hospital, the percentage of participants on the CST interventions living at home was lower at 71.9%. Most participants were living in urban areas, although the percentage varied between 55.6% and 67.5% depending on intervention type.

Table 5: Characteristics of people with dementia participating by intervention type

	Cognitive Stimulation Therapy interventions (n=89)	Cognitive Rehabilitation interventions (n=80)	Psychoeducational interventions (n=63)
<b>Sex, n (%)</b>			
Male	37 (41.6)	33 (41.3)	23 (36.5)
Female	52 (58.4)	47 (58.8)	40 (63.5)
<b>Age, mean (SD), range</b>	80 (8.0), 58-95	76 (7.7), 55-89	77 (8.6), 52-91
<b>Age groups, n (%)</b>			
<65 years	3 (3.4)	7 (8.8)	5 (7.9)
65-74 years	18 (20.2)	25 (33.3)	16 (25.4)
75-84 years	40 (44.9)	40 (50.0)	31 (49.2)
85-94 years	27 (30.3)	8 (10.0)	11 (17.5)
95+ years	1 (1.1)	0 (0.0)	0 (0.00)
<b>Education level, n (%)</b>			
Primary education or less	21 (23.6)	16 (20.0)	14 (22.2)
Secondary education	37 (41.6)	35 (43.8)	40 (63.5)
Third level or further education	22 (24.7)	28 (35.0)	1 (1.6)
Don't know / Not stated	9 (10.1)	1 (1.3)	8 (12.7)
<b>Marital Status, n (%)</b>			
Married	52 (58.4)	53 (66.3)	40 (63.5)
Widowed	23 (25.8)	17 (21.3)	18 (28.6)
Single	9 (10.1)	4 (5.0)	4 (6.3)
Separated/Divorced	4 (4.5)	5 (6.3)	1 (1.6)
Other	1 (1.1)	1 (1.3)	0 (0.00)
<b>Living arrangements, n (%)</b>			
With Spouse/partner	48 (53.9)	50 (62.5)	38 (60.3)
Alone	24 (27.0)	20 (25.0)	14 (22.2)
With son/daughter	12 (13.5)	5 (6.3)	7 (11.1)
With other family	2 (2.2)	2 (2.5)	3 (4.8)
With other	3 (3.4)	3 (3.8)	1 (1.6)
<b>Principal Carer, n (%)</b>			
Spouse/Partner	40 (46.0)	43 (53.8)	38 (60.3)
Adult child	31 (35.6)	18 (22.6)	17 (27.0)
Sibling	1 (1.1)	0 (0.0)	0 (0.0)
Other	9 (10.3)	6 (7.6)	5 (7.9)
None	6 (6.9)	13 (16.3)	3 (4.8)
<b>Current accommodation, n (%)</b>			
Own home	64 (71.9)	77 (96.3)	60 (95.2)
Acute hospital	21 (23.6)	0 (0.0)	0 (0.0)
Nursing Home / Community Nursing Unit	2 (2.2)	0 (0.0)	1 (1.6)
Support housing	1 (1.1)	0 (0.0)	0 (0.0)
Other / Not known	1 (1.1)	3 (3.8)	2 (3.2)
<b>Location, n (%)</b>			
Urban	56 (62.9)	54 (67.5)	28 (55.6)
Rural	33 (37.1)	26 (32.5)	35 (44.4)

## 5.2 Recruitment, referral and selection of participants to interventions

The grantees invested much of their time to make the interventions work including recruitment of interventions participants. The time invested, strategies developed and challenges surrounding the recruitment of people with dementia and/or family carers to the interventions was a recurring theme. The 17 projects can be loosely divided into those that reported recruitment to be 'good' and 'as expected' in that there was a steady flow of referrals for the intervention; and those that described recruitment as 'slow' and that demand for the intervention was less than anticipated.

Projects that described recruitment as 'good' tended to be based in HSE services such as memory clinic, community mental health, day hospital and OT services, many based on a hospital campus. They had good knowledge of referral pathways and pre-existing relationships and networks with health professionals and health services in the locality. They knew their clientele well and some had a cohort of people already earmarked as potentially suitable for the intervention. They generally reported good links with and a direct line of referral from diagnostic services, either memory clinic services, or geriatricians and psychiatrists in day hospitals or community mental health teams, which was particularly important for identifying people with dementia at the earlier stages of dementia. Crucially, they had also developed strategies for promoting the intervention, making it known to the relevant health professionals and services, and increasing its acceptability, but they stressed that recruitment requires 'know-how', time and effort.

Strategies included presenting the intervention to consultants at journal club meetings, or inviting health professionals to attend a group session to see for themselves the intervention in practice, how it works and what the benefits are for participants. Another strategy was to inform referrers of referral outcomes, but the administration involved in providing this detailed information is time-consuming. The reputation of health professionals delivering the intervention also had an impact on recruitment. The availability of funding also created a higher expectation among potential participants that the intervention would be delivered. Staff felt more confident reaching out to health professionals to seek referrals, and were in a position to assure people with dementia referred that the intervention would definitely run.

However, some projects still experienced difficulties with recruitment. Delays in recruiting staff had an effect on participant recruitment, but other issues were also at play. Stigma was reported by some projects, especially those running group interventions and in counties with large rural areas, as a barrier to recruitment. Some projects with lower than expected interest extended their catchment area, but this resulted in longer travel distances for participants to get to the venue, or when the intervention was provided in the person's home it meant that staff had to travel further, which increased service delivery costs.

It was not good practice to recruit people with dementia and then place them on a waiting list until an intervention was 'ready to go' or until enough people were recruited to start a group intervention. Projects that did this found that people were often disappointed when they heard that the intervention could not start straight away or in the near future. When project staff got back in touch with these people at a later date, they found that many were either no longer interested in participating or could not participate due to cognitive decline. Participants were referred to the interventions from a variety of services and by a wide range of health professionals (Tables 6 and 7).

Table 6: Services referring people with dementia by intervention type

Referral Source - Service n (%)	CST (n=89)	CR (n=80)	PEP (n=86)
Memory clinic / service	16 (18.0)	23 (28.8)	3 (3.5)
Primary care	10 (11.2)	16 (20.0)	15 (17.4)
Community mental health	18 (20.2)	1 (1.3)	9 (10.5)
Day hospital	0 (0.0)	10 (12.5)	17 (19.8)
Hospital out-patient clinic	4 (4.5)	11 (13.8)	12 (14.0)
Hospital in-patient service	22 (24.7)	5 (6.3)	0 (0.0)
Alzheimer's Association	10 (11.2)	0 (0.0)	3 (3.5)
Day care centre	2 (2.2)	0 (0.0)	0 (0.0)
Memory Technology Resource Room	0 (0.0)	3 (3.8)	0 (0.0)
Older Persons Integrated Care Team	0 (0.0)	2 (2.5)	0 (0.0)
Self-referral	2 (2.2)	1 (1.3)	21 (24.4)
Other	5 (5.6)	8 (10.0)	5 (5.8)

Table 7: Health professionals referring people with dementia by intervention type

Referral Source - Health professional n (%)	CST (n=80)	CR (n=80)	PEP (n=80)
Geriatrician	15 (16.9)	15 (18.8)	30 (37.5)
Old age psychiatrist	12 (13.5)	2 (2.5)	5 (6.3)
GP	1 (1.1)	1 (1.3)	13 (16.3)
PHN	6 (6.7)	9 (11.3)	1 (1.2)
OT	14 (15.7)	32 (40.0)	1 (1.2)
Social worker	0 (0.0)	9 (11.3)	1 (1.2)
S&LT	4 (4.5)	0 (0.0)	0 (0.0)
CMHN	4 (4.5)	0 (0.0)	2 (2.5)
Nurse	15 (16.9)	9 (11.3)	5 (6.3)
Dementia care coordinator	0 (0.0)	0 (0.0)	1 (1.2)
Psychologist	1 (1.1)	0 (0.0)	0 (0.0)
Dementia Advisor	3 (3.4)	0 (0.0)	0 (0.0)
Self-referral	0 (0.0)	1 (1.3)	21 (26.3)
Other	11 (12.4)	2 (2.5)	0 (0.0)

For the CST interventions, approximately a quarter of participants were referred from within a hospital, which is to be expected given that a quarter of participants took part in a CST intervention delivered in a hospital in-patient setting. While successful at recruiting people with dementia to the intervention, this hospital project found the process of identifying people with dementia on older people's wards hugely challenging, due to poor recording of a dementia diagnosis among hospital in-patients. For the community-based CST programmes, the services most frequently referring people with dementia were community mental health, memory clinic and primary care services. Geriatricians, old age psychiatrists, nurses (not PHNs) and OTs were the health professionals that most frequently referred people with dementia to the CST interventions (Table 8). Just over 10% of participants were referred by Alzheimer Associations. Projects that relied solely on reaching people with dementia directly or on referrals from voluntary sector organisations found recruitment very challenging. For example, one organisation, despite advertising the intervention in a myriad of ways (i.e. advertisement posters, voluntary sector services and websites, local newspapers, radio, Dementia Advisors) got little response to the advertisements.



For CR, the participants were most frequently referred by memory clinics (28.8%), followed by primary care services (20.0%), hospital out-patient clinics (13.8%) and day hospitals (12.5%). People with dementia were most frequently referred to CR programmes by OTs, who were the source of referral for 40% of participants (Table 6), which is likely to reflect existing relationships and networks, given that many of the CR interventions were initiated by OTs. Geriatricians, social workers, PHNs and other nurses were also relatively frequent referrers of people with dementia to CR interventions (Table 7).

For the PE interventions, 53 people with dementia attended a group or individual intervention with a family member, 23 family carers participated without a relative with dementia, and 10 people with dementia participated without a family carer. The results on referral to PE interventions presented in Table 6 therefore relate to 86 dyads or individuals and a slightly smaller number in Table 7 due to missing information. In contrast to the CST and CR interventions, which had few self-referrals, a quarter of referrals to PE interventions were self-referrals (Table 6). All of these self-referrals were to PE interventions run by one project and included self-referrals from family carers who wished to attend a group PE intervention for family carers only, and from people with dementia who participated in an individual PE intervention for people with dementia only. Day hospitals (19.8%), primary care (17.5%) and hospital out-patient clinics (14.0%) figured strongly among services referring people with dementia to PE interventions. Geriatricians made more than one-third (37.5%) of the referrals to PE interventions. In contrast to the other CST and CR interventions, GPs made one in six (13%) of the referrals to the PE interventions. The majority of referrals from GPs were linked to one project (Table 7), but other projects reported an unwillingness among GPs generally to refer family carers to a PDS intervention.

The quality of referrals and level of inappropriate referrals was highlighted as problematic by many of the projects, and a wide range of issues were highlighted. People with dementia were being referred to the intervention too soon after diagnosis, before they had time to come to terms with the diagnosis, or too late in their disease progression for it to be appropriate or effective. People with dementia were being referred to the intervention, even though they had no transport or way of getting to the service. Some projects took steps to minimise the level of inappropriate referrals. One approach was to only accept referrals from a limited range of health professionals and invest time in informing and educating these health professionals about the intervention, participant suitability and selection criteria. Over time, referrals were opened up to other health professionals once they too had been informed and educated about the intervention.

The selection criteria for the interventions used by projects varied. In selecting participants for CST groups, several grantees had given consideration to how people would interact in the groups and had carefully selected participants to ensure that people in the group got along. They explained that this was important for the group to work successfully and to maximise the benefits of the intervention for the participants. This was harder to do in some settings such as acute hospital settings and day care centres. Some projects could not do this due to low recruitment rates. Given the interactive nature of CST, it was a challenge to accommodate and meet the needs of people with additional difficulties such as hearing, sight or communication difficulties or responsive behaviour in the groups, and although this was possible, it required one-to-one interaction, and could distract attention away from other group members. Issues such as how well the person was, and infection control were additional issues that had to be considered when selecting participants for the in-hospital CST intervention.

### 5.3 Diagnosis and diagnostic issues

The vast majority (>90%) of participants with dementia across the three intervention types had a formal diagnosis of dementia, although there were a small number of people who health professionals suspected had dementia, but no formal diagnosis had been made or else the diagnostic decision was awaited (Table 8).

Despite the high proportion of participants who had been formally diagnosed, many issues were raised by grantees regarding diagnosis. Some grantees reported that a lot of time and effort had gone into confirming that persons referred had a formal diagnosis. They also had to find out if a diagnosis had been disclosed to the person and were conscious that when delivering the intervention that a diagnosis may not have been disclosed. Thus, some projects reported using both the terms 'dementia' and 'memory problems' in group sessions to cover ambiguities in diagnosis. Grantees stressed that how the disclosure had been made to the person had implications for post-diagnostic supports. For example, if a person is informed by a doctor about their diagnosis but told that they can carry on as usual, without the need for any intervention for the time being, this person may be less inclined to see the need for a PDS intervention such as CR or PE when it is offered. This issue then has to be addressed by intervention providers. At the other extreme, if a diagnosis of dementia had been communicated in very bleak terms without discussion of what can be done to maintain ability and live well with dementia, the person may be overwhelmed by the news and possibly view dementia nihilistically. Even where the diagnosis has been disclosed well, some people may find it hard to come to terms with the diagnosis, feel hopeless, or perhaps lack insight.

Grantees in some areas, particularly counties with large rural areas, reported a reluctance by some people with dementia to enrol in PDS interventions, especially group interventions, which may be explained by non-acceptance of a dementia diagnosis or stigma associated with a dementia diagnosis. In some cases, it was simply that supports were offered too early after the diagnosis and the person needed time to come to terms with the diagnosis. Furthermore, it was not unusual for issues related to diagnosis such as disclosure, non-acceptance, stigma or lack of awareness to occur during intervention sessions. These were issues that the projects had to consider as part of intervention implementation and required skill on the part of the facilitators to address these issues in a sensitive, transparent and appropriate manner when and as they arise during sessions.

Table 5: Characteristics of people with dementia participating by intervention type

	CST programmes (n=89)	Cognitive rehabilitation programmes (n=80)	Psychoeducational programmes (n=63)
<b>Formal dementia diagnosis</b>			
Yes	82 (92.1)	77 (96.3)	61 (96.8)
No	6 (6.7)	2 (2.5)	2 (3.2)
Unsure	1 (1.1)	1 (1.3)	0 (0.0)
<b>Dementia sub-type n</b>			
Alzheimer's disease	30 (33.7)	29 (36.3)	27 (38.1)
Vascular Dementia	21 (23.6)	15 (18.8)	7 (11.1)
Lewy Body Dementia	4 (4.5)	1 (1.3)	2 (3.2)
Frontotemporal dementia	0 (0.0)	1 (1.3)	0 (0.0)
Parkinson's Disease Dementia	1 (1.1)	1 (1.3)	0 (0.0)
Stroke-related /ABI-related dementia	2 (2.2)	1 (1.3)	0 (0.0)
Early onset dementia	0 (0.0)	2 (2.5)	0 (0.0)
Mixed dementia	5 (5.6)	4 (5.1)	4 (6.4)
Sub-type not specified/known	26 (29.2)	26 (32.6)	26 (41.3)
<b>Months diagnosed</b>			
Range	1-228	1-90	1-72
Mean (SD)	30.5 (36.5)	16.2 (19.2)	10.9 (14.6)
Median	24	8	4
<b>Time since diagnosis, n, (%)</b>			
6 months or less	21 (30.0)	35 (46.7)	36 (59.0)
Between 6 months and 1 year	10 (14.3)	15 (20.0)	12 (19.7)
Between 1 and 2 years	9 (12.9)	10 (13.3)	9 (14.8)
Between 2 and 3 years	13 (18.6)	6 (8.0)	1 (1.6)
Between 3 and 4 years	5 (7.1)	4 (5.3)	0 (0.0)
Between 4 and 5 years	6 (8.6)	5 (6.7)	2 (3.3)
More than 5 years	6 (8.6)	0 (0.0)	1 (1.6)
<b>Dementia severity, n (%)</b>			
Mild	24 (27.0)	59 (73.8)	19 (30.2)
Moderate	27 (30.3)	15 (18.8)	28 (44.4)
Severe	11 (12.4)	0 (0.0)	3 (4.8)
Not specified/known	27 (30.3)	6 (7.5)	13 (20.6)
<b>Person recognises dementia</b>			
Yes (including some insight)	62 (69.7%)	65 (81.3%)	47 (74.6)
No	21 (23.6%)	6 (7.5%)	13 (20.6)
Don't know / Not stated	6 (6.7%)	9 (11.3%)	3 (4.8)

The sub-type of dementia was not known for between about 30% and 40% of participants depending on the programme type. Among those whose type of dementia was known, participants mostly presented with Alzheimer's disease, followed by Vascular Dementia and Mixed dementia. There was also a small number of participants with less common forms of dementia such as Lewy Body Dementia.

Because a dementia diagnosis does not occur at a set time for everyone and a time limit since diagnosis is not usually specified for post-diagnostic support, it is difficult to stipulate when post-diagnostic supports should begin and end. But, because some post-diagnostic supports work most effectively when provided at the early stages of the disease and may not be appropriate at the later stages (O'Shea et al., 2018), it is useful to consider both time since diagnosis and the stage of dementia of PDS intervention participants. The time since diagnosis was available for 206 (88.9%) intervention participants, although there was much variation across intervention types (Table 8). The average time since diagnosis was 31 months for people with dementia participating in CST, 16 months for people in CR and 11 months for those in PE interventions.

Looking specifically at different intervention types, less than one-half (44.3%) of people with dementia participating in CST interventions had received a diagnosis of dementia within one year prior to commencing the intervention, and there were wide-ranging differences among projects, ranging from 0% to 72%. The stage of dementia was available for approximately 70% of people with dementia participating in the CST programmes (Table 8). Of these participants, the majority has either mild (38.7%) or moderate (43.5%), but there was also a sizeable proportion (17.7%) of people with severe dementia participating in CST programmes. While CST has been shown to be most appropriate for people with mild to moderate dementia (Aguirre et al., 2013), many of the projects in the NDO's PDS Grant Scheme delivering CST believed that people with advanced dementia participating benefited from the intervention.

The proportion of people who had received a diagnosis of dementia within one year or less rose to two-thirds (66.7%) for CR interventions. Among those for whom dementia severity was available, four out of five (79.7%) had mild dementia, and the remaining one-fifth moderate dementia. CR interventions are most appropriate for people with dementia at the early stages of the disease, and it would seem that the projects delivering CR interventions in the NDO's PDS programme were targeting their interventions to people with dementia soon after diagnosis and at the mild to moderate stages of the disease.

For the PE interventions, the proportion of people who had received a diagnosis of dementia within one year or less was more than three-quarters (78.7%). The stage of dementia was not available for one-fifth of participants on the psychoeducational interventions, but among those for whom it was, over one-half (56.0%) were in the moderate stages of dementia, and over one-third (38%) had mild dementia. A small number of people with severe dementia also participated in PE interventions. This included individualised PE interventions for people with dementia only, and the value of this for people with advanced dementia is questionable.

There were people with no insight or recognition that they had dementia across all three interventions types. The proportion was relatively low for participants in CR interventions (7.5%). This is still important as lack of insight may act as a barrier to CR intervention engagement and affect intervention outcomes, and specific strategies need to be adopted for CR to become a viable option for people who lack awareness or insight into their condition (Choi and Twamley, 2013). The adoption of such strategies to improve intervention engagement and outcomes is also relevant for CST and PE interventions, given that there were about one in five participants who did not recognise that they had dementia.

#### **5.4 Family carers attending / participating in PDS programmes**

Apart from one case, family carers did not attend or participate in the CST interventions, although family carers were often needed to accompany the person with dementia to the intervention venue.

A total of 64 family carers attended the CR interventions with their relative with dementia and 75 family carers participated in PE interventions. The characteristics of these family carers are presented in Table 9, which shows a similar profile for participants of both interventions. The

majority of family carers were female. They ranged in age from their early 30s to their late 80s and on average were aged in their early 60s. Approximately half were aged under 65 years of age, and more than one quarter were 75 years and older. The majority of family carers had completed secondary level education or higher, reflecting the preponderance of younger carers.

With regard to the relationship of the family carer to the person with dementia, just over half were a spouse or partner, and more than one-third were an adult child. The majority (>80%) were married, although there was a higher proportion of single people among family carers participating in PE interventions. Approximately 60% of family carers on both intervention types lived with the person with dementia. The greatest difference between family carers was where they lived. A higher proportion of family carers participating in CR interventions lived in a rural area (60%) than those participating in PE interventions (50%), similar to participants with dementia.

**Table 5: Characteristics of people with dementia participating by intervention type**

	Cognitive Rehabilitation interventions (n=64)	Psychoeducational interventions (n=76)
<b>Sex, n (%)</b>		
Male	19 (30.2)	20 (26.3)
Female	44 (69.8)	56 (73.7)
<b>Age, mean (SD), range</b>	64 (15.3), 32-87	62 (14.5), 31-86
<b>Age groups, n (%)</b>	(n=43)	
<65 years	21 (48.8)	41 (53.9)
65-74 years	8 (18.6)	12 (15.8)
75-84 years	11 (25.6)	21 (27.6)
85-94 years	3 (7.0)	2 (2.6)
95+ years	0 (0.0)	0 (0.0)
<b>Education level, n (%)</b>		
Primary education or less	6 (9.4)	14 (18.4)
Secondary education	23 (35.9)	34 (44.7)
Third level or further education	21 (32.8)	22 (28.9)
Don't know / Not stated	14 (21.9)	6 (7.9)
<b>Marital Status, n (%)</b>		
Married	57 (89.1)	64 (84.2)
Widowed	0 (0.0)	0 (0.0)
Single	1 (1.6)	11 (14.5)
Separated/Divorced	3 (4.7)	1 (1.3)
Don't know / Not stated	3 (4.7)	0 (0.0)
<b>Location, n (%)</b>		
Urban	38 (60.3)	38 (50.0)
Rural	25 (39.7)	38 (50.0)
<b>Lives with person with dementia, n (%)</b>		
Yes	37 (58.7)	47 (61.8)
No	26 (41.3)	29 (38.2)
<b>Relationship to person with dementia, n (%)</b>		
Spouse/Partner	34 (54.0)	39 (52.0)
Adult child	22 (34.9)	32 (42.7)
Other related person	5 (8.0)	4 (5.3)
Other	2 (3.2)	0 (0.0)

## 5.5 Access to PDS interventions

The majority of the 89 people with dementia participating in CST interventions were community-based, 21 were in-patients in an acute hospital and accessed the intervention during their hospital stay, and two were residing in a community nursing unit where the intervention was held. While people with dementia in hospital wards did not have to travel to the interventions, getting patients to and from the sessions was not without its challenges for staff and this had to be factored in when planning implementation.

For 17 of the 80 participants on CR interventions and 26 of the 86 dyads or individuals on the PE interventions, staff delivering the intervention travelled to the person's home or place of residence, and hence there was no travel involved for the person with dementia and/or family carer. However, projects delivering these interventions highlighted the long distances that staff had to travel and the high costs associated, especially in counties spread over large geographical areas with small rural communities.

Participants with dementia who travelled to the CST, CR and PE interventions used a variety of modes of transport, most frequently as a passenger in a car. The latter required someone to be available to drive the person to the venue, and most people had family members and friends who committed to doing this. In interviews, grantees stressed that families play a vital role in getting people to the intervention and to the success of the intervention. Approximately 10% of participants with dementia in the CST and CR interventions travelled to the venue driving a car, which staff had to be aware of and be ready to address any issues that arose, for example, helping the person to find parking in a large, busy hospital car park. A small number walked to it on foot or used taxis or trains (Table 10). A small number of people could not complete the interventions due to transport issues.

The time it took for participants with dementia to get to the intervention venue ranged from 5 minutes to 1 hour 20 minutes. It took on average between 17 and 25 minutes depending on intervention type. The distance participants with dementia travelled ranged from 1 km to as far as 60 kms away (which was to a venue in Dublin) and on average they travelled between 9 and 14 kms to attend the interventions.

**Table 10: Mode of transport, travel time and distance by intervention type (Person with dementia)**

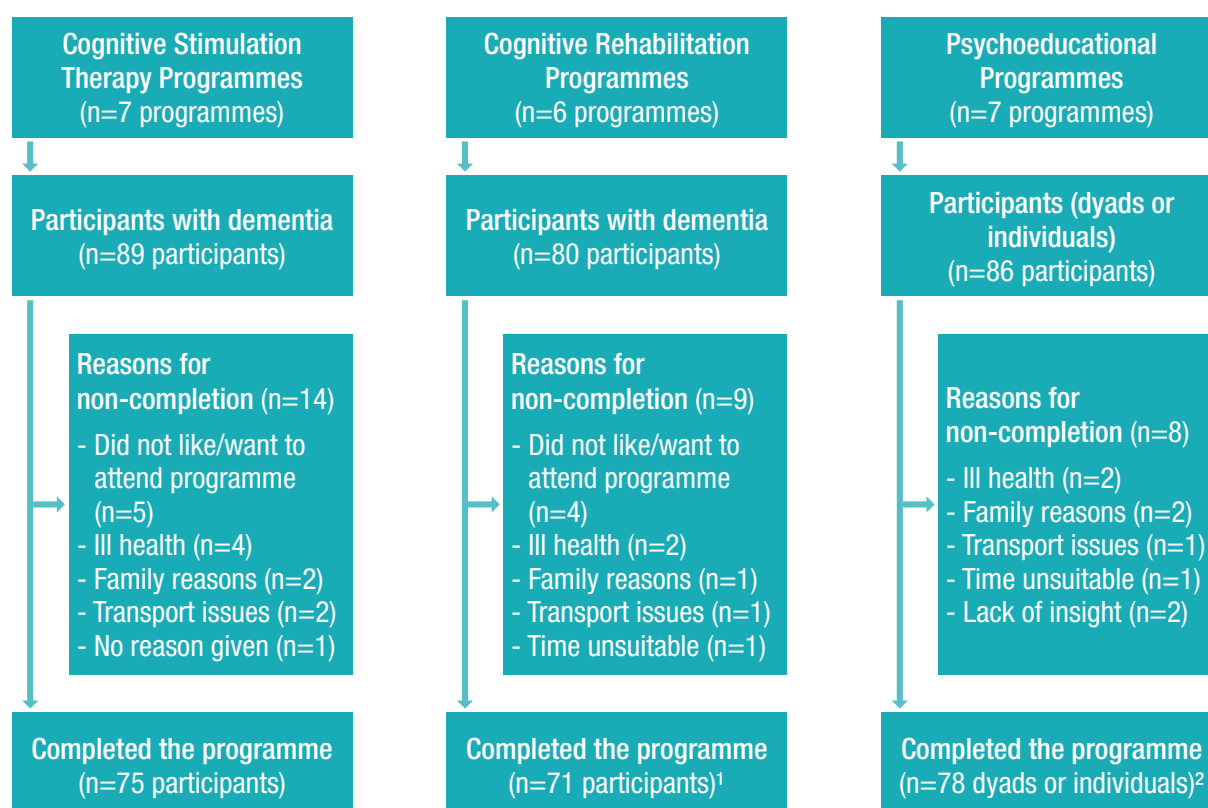
	CST interventions (n=89)	Cognitive rehabilitation interventions (n=80)	Psychoeducational interventions (n=63)
<b>Mode of transport</b>			
Passenger in a car	37 (41.6)	40 (50.0)	35 (40.7)
Driving a car	11 (12.2)	8 (10.0)	1 (1.2)
Bus, minibus, coach	10 (11.2)	5 (6.3)	0 (0.0)
On foot	4 (4.5)	3 (3.5)	0 (0.0)
Train, Dart or Luas	0 (0.0)	4 (5.0)	0 (0.0)
Taxi	3 (3.4)	3 (3.5)	1 (1.2)
More than one mode	1 (1.1)	0 (0.0)	0 (0.0)
Not applicable	23 (25.6)	17 (21.5)	26 (57.0)
Travel time in minutes, mean (SD), range	20.7 (12.8), 5-60	24.3 (16.8), 3-80	17.4 (10.3), 5-45
Travel distance in kms, mean (SD), range		14.2 (14.1), 1-60	9.1 (8.0), 1-32

In interviews, grantees highlighted other access issues that they had to be aware of, attentive to and find solutions. In addition to finding and directing people to suitable parking, entry to, exit from and circulation within buildings could pose challenges. For example, in a hospital setting, there may be more than one entrance and group facilitators had to be aware of which entrance participants used to come in and guide them back there on their way out. In one large hospital setting, because of difficulties finding the room, the group facilitator arranged to meet the participants at a central location within the building and bring them together to the room so as to minimise stress and avoid people arriving late or missing the session. In some buildings, entry doors were pin protected or card operated, and this was an added complication for people with dementia trying to gain access to rooms where the intervention was held. During session breaks, some participants needed help finding their way to and from the bathroom. Some group facilitators were able to alert and enrol the help of staff in the building, e.g. porters or receptionists, with these issues, but others found staff reluctant to help.

### 5.6 PDS intervention completion and attendance

Of the 255 dyads or individuals who enrolled on the PDS interventions, the majority (87.8%) were reported to have completed the intervention. In total across the three intervention types, 224 dyads or individuals completed the intervention (Diagram 3). Some 31 dyads or individuals did not complete the interventions and a variety of reasons were given for this. Some people with dementia did not like or want to attend the intervention and some could not complete it due to ill-health, including hospitalisation. A small number could not attend because of transport issues or because of family reasons such as a family bereavement and family work or other commitments. Other reasons were that the person with dementia lacked insight or the time of the intervention was unsuitable.

**Diagram 3: Intervention completion and reasons for non-completion**



*Notes:* <sup>1</sup>Of the 64 family carers who attended CR with a person with dementia, 53 completed the intervention. Seven did not finish the intervention because the person with dementia dropped out. Others could not attend all of the intervention due to work or family commitments, but attended when they could. In a few cases, different family members attended different sessions;

<sup>2</sup>Of the 76 family carers who participated in PE interventions, 70 completed the intervention. Six could not complete the intervention due to a variety of reasons such as unsuitable time, work commitments, ill health of person with dementia, lack of insight of person with dementia and transport issues.

Intervention attendance is presented in Table 11 and relates to those who completed closed interventions. It is important to remember that there was much variation both between and within intervention types with regard to intervention format and number of sessions/weeks, as shown in Section 4.1. The four CST closed interventions delivered the intervention once-weekly over either 7, 8 or 14 weeks (Table 1). The CR interventions in the PDS Grant Scheme provided sessions once weekly between 4 and 7 weeks (Table 2). PE interventions were delivered once-weekly over 4, 5, or 6 weeks (Table 3). This variation needs to be borne in mind when examining the overall results on attendance in Table 10, which shows the proportion of sessions that participants attended CST interventions (closed), CR programmes and PE interventions.

**Table 11: Attendance by intervention type**

	<b>CST closed group interventions (n=61)</b>	<b>Cognitive rehabilitation interventions (n=71)</b>	<b>Psychoeducational interventions (n=78)</b>
<b>Proportion of sessions attended, n (%)</b>			
All	13 (21.3)	59 (83.1)	46 (53.5)
At least 75% but not all	24 (39.3)	10 (14.1)	17 (19.8)
At least 50% but less than 75%	14 (23.0)	2 (2.8)	6 (7.0)
At least 1 session but less than 50%	7 (11.5)	0 (0.0)	8 (9.3)
Attended none	3 (4.9)	0 (0.0)	1 (1.2)

Attendance of those who completed an intervention varied among intervention types (Table 11). Four-fifths of participants on CR interventions, approximately half of participants on PE interventions and one-fifth of participants on CST interventions attended all sessions. This is likely to be linked to the number of sessions that participants had to attend to achieve full participation. For example, it may be harder for people to attend all sessions of a 14-week CST intervention than a four-week CR intervention. While CST had the lowest full attendance of the three intervention types, the percentage of participants who attended 50% or more of the CST sessions (83.6%) is comparable to findings on CST attendance in the UK Shield study which reported that 81% of participants attended at least half of the CST sessions (Orrell et al., 2017).

Two projects delivered CST interventions on an open format (Table 1). Attendance at the CST open interventions ranged from three sessions to 22 sessions, and participants attended an average of nine sessions. There was a large difference between these two interventions regarding the average number of sessions attended by participants, with people with dementia on the community-based intervention attending a greater number of sessions (mean = 14 sessions) than those on the in-hospital based intervention (mean = 8 sessions).



## 6 Impact evaluation

***“I understand why you ask these questions. Everything of value must be measured.”***  
(CST participant)

People with dementia who participated in CST, CR and PE interventions and family carers who participated in PE interventions completed an evaluation form at the end of the intervention. The above quote is a comment from an evaluation form completed by one person with dementia. In total, 174 people with dementia and 61 family carers completed an evaluation form. The section reports on the findings from the evaluation forms. The impact of the interventions was also discussed in interviews with staff involved in implementing the CST, CR and PE interventions, and these findings are also reported here.

Overall, the responses of people with dementia to all three intervention types were extremely positive (see Appendix B, Tables B1-B4). Six items (Items 1, 11, 13, 14, 15 and 17) were core items, common to each of the three questionnaires developed to assess the impact of the three intervention types. People who have complete individual interventions, however, were not presented with items 13, 14 and 15, as these items related solely to group interventions. The findings from the core items are as follows.

**Value of the intervention (Item 1):** An overwhelming majority ( $\geq 97\%$ ) of people with dementia who responded stated that taking part in the CST, CR and PE interventions was of value to them. All of the family carers agreed that the PE intervention was of value to them.

**Confidence (Item 11):** Participants with dementia (family carers) in the three intervention types were asked to respond to the following statement: 'Having completed the programme, I now feel more comfortable speaking about my memory problems/dementia (or my relatives/friends memory problems/dementia)'. Nearly all participants with dementia on the CR (93.0%) and PE (94.7%) interventions responded 'Yes' to this statement. However, a lower proportion (71.2%) participating on the CST interventions agreed with this statement, and the majority of these negative responses were linked to one organisation delivering CST interventions.

**Connectedness (Items 13, 14 and 15):** For those participating in groups CST, CR and PR interventions, all or nearly all responded positively to the three statements related to connectedness - '*I like the atmosphere in the group*'; '*The people in the group support each other*'; and '*The programme gave me an opportunity to meet other people in a similar situation to me. This was of benefit to me*'.

**Would recommend intervention (Item 17):** The vast majority ( $>95\%$ ) of participants on the CST, CR and PE interventions would recommend the intervention to another person.

### 6.1 Cognitive Stimulation Therapy

CST has been shown to be effective with regard to cognition and quality of life (Spector et al., 2003). Improved cognition (in areas such as concentration, organisation and thinking) and quality of life were identified by grantees as expected benefits for people with dementia. Three-quarters ( $n=67$ ) of people with dementia who participated in the CST interventions completed an outcomes evaluation form. Eight people with dementia, in their comments about the intervention referred to the benefits of CST to them, either generally 'I got a lot out of it', or specifically to cognitive and social benefits: "*Keeps memory active, abreast with current affairs, helps my social life...*".

Grantees, in interviews, discussed the mechanisms by which CST groups might generate such outcomes. Mental stimulation is one of the principles that must be incorporated into CST sessions. The activities in the CST groups were seen by grantees to be an important mechanism for stimulating or activating cognition. They reported that people tend to warm up over the course of each session, and overtime peoples' alertness and concentration improved and their capacity to engage in conversation on current affairs and a wide range of topics increased. The vast majority (95.5%) of people with dementia who completed evaluation forms responded that they enjoyed the conversations in the group, and a smaller majority of three-quarters (74.6%) agreed that the activities in the group were relevant to their everyday needs. A majority (85.1%) agreed that *'Doing the activities gave me a sense of achievement'*.

Engagement, another principle of CST, was seen to be very important by grantees who reported that the social interaction together with the content and activities seemed to make a difference. The activities in a group setting were believed to be helping participants to maintain social skills. Grantees reported that people with dementia often had very little to do. As one interviewee put it *'If they are not here at this group, they don't have a whole lot else going on.'* They reported that the activities and engagement brought people *'out of themselves'*, possibly helping them to dwell less on their problems or anxieties. Improvements in cognition and increased social interaction were believed to lead to increased confidence. Engagement in group discussions might also be thought of as enabling people with dementia to grow, and a large majority (92.4%) of people with dementia agreed with the statement: *'In this group, I had an opportunity to hear people's views. This broadened my outlook on life'*. An added benefit of participation, according to grantees, was that it gave people something to talk about with family at home. For staff on one project, a key outcome is that the voices of people with dementia will be heard. In their everyday lives, people with dementia don't always have an opportunity to 'talk' and CST fills an important gap.

The statements on the evaluation form that received the highest proportion of positive responses from people with dementia participating in CST related to 'joy'. Almost all (>98%) agreed with the two statements: *'The group is pleasant. I feel able to relax and enjoy coming to the group'* and *'I enjoyed the activities'*. The enjoyment that people experienced in the CST groups was borne out by comments that participants made: *"How much I enjoyed it and will miss the chat and fun we had. [Names of group facilitators] were a pleasure to be with. Thank you so much"*.

Grantees described the importance of the atmosphere in the sessions. Where the atmosphere was positive (i.e. there was lots of talking, laughing, singing, sharing of experiences, views, opinions and anecdotes) and participants were happy, it helped people attending make close bonds with both staff and other participants. More than 95% of people with dementia participating in CST interventions responded 'Yes' to the statement *'I like the atmosphere in the group'*.

Grantees stressed that the atmosphere had to be such that people could feel safe sharing stories with each other. Two statements in the evaluation form related to Security / Safety. The vast majority of participants agreed that *'I feel safe expressing opinions in the group'* (95.5%), but a lower percentage, although still a majority, agreed that *'I feel safe sharing difficulties or problems life throws at me with the group'* (75.0%). Negative responses to this statement were not confined to one particular project, perhaps suggesting that a CST group may not always be the right environment for addressing personal or complex difficulties or problems that people with dementia may be experiencing.

The flexibility of CST was identified by grantees as being important. Having the flexibility to personalise each session to the group within the overall CST structure was an important aspect of the intervention and allowed staff to respond and tailor the sessions when for example, people in the group were having a problem with an activity. Grantees stressed that it was important to ensure that participation was given priority over the content of the session, which is

consistent with the principle of inclusion, another principle of CST. All (100%) of the people with dementia who participated in CST and completed an evaluation form agreed with the statement 'I can be myself here' and almost all (97%) with the statement '*People in the group took time to talk to me and listen to me*'. It was also important for staff to hear from and about people in the group, and that they feel listened to and heard as a person.

The grantees, in interviews, suggested that peer support was an important aspect of CST. Having the opportunity to be in an enjoyable environment with other people with dementia was a normalising mechanism and grantees reported that participants felt a sense of belonging when they saw that they are all in the same boat. The importance of connectedness, especially the opportunity to meet with and talk to other people, was also commented upon by people with dementia in the evaluation form. The support was important to people as it made them feel that they were not alone and isolated: "*I loved that, when asked about meeting other people in similar situations*" or "*Nice to know I am not alone*".

The impact that a diagnosis of dementia may have on individuals was evident in comments made by a few people with dementia participating in CST - "*It's good. Fair play to yis for having it. When I was told about my dementia, I went upstairs for a cry but then I was ok.*" This highlights the need for group facilitators to be aware of and sensitive to individual needs. Peer support, it was suggested by grantees, could help alleviate some of the sadness or fear surrounding a diagnosis of dementia, and can lead to a reduction in shame and stigma. One person described CST as "*enlightening for me as an individual as to my scope for my life and being self-sufficient. Dementia is dehumanising a human being,*" perhaps suggesting that the intervention may have a role to play in helping people to cope with not only the psychological and emotional impact of a dementia diagnosis but also stigma associated with it. However, while the majority (71.2%) of people with dementia participating in CST agreed that 'Having completed the programme, I now feel more comfortable speaking about my memory problems/dementia', this was lower than the proportion of people with dementia (>90%) in CR and PE interventions who agreed with this statement.

As well as the benefits for people with dementia, grantees spoke about benefits of CST for staff. Some staff reported that the positive atmosphere was not only therapeutic for people with dementia but also for staff delivering the sessions. Some found that CST opens up discussions that allowed people with dementia '*show another side of themselves*', often a 'side' of the person not generally seen by staff. This was important for staff because it enabled staff not only to 'see' the person with dementia but get to really '*know*' the person. It gave staff a much better picture of the person and their family and a greater sense of who they are as people. It reminded staff of the strengths of individuals with dementia and it refreshed and reinforced person-centred care. In this way, the intervention was described as '*special*'. The contribution that people with dementia can make was also highlighted. The extent to which people with dementia can contribute to discussion had taken two very experienced health professionals by surprise, and using an example of a discussion about stigma that came up in one group, explained that even people who don't participate hugely can provide really interesting insights and make significant contributions, which can help bring fresh perspectives to complex issues under discussion.

Grantees remarked that the participants presented themselves very well, which was an indication that they were making an effort to look well and smart when coming to meet other people, but it was also an indication for staff that they were managing activities of daily living well such as washing, dressing and looking after their appearance. On one project, staff explained that the intervention also gave them an opportunity to unobtrusively assess how people were faring at home and to intervene and seek appropriate support for them (e.g. arrange consultation with geriatrician for medication review, telephone call to PHN to suggest a review of home supports) if they noticed any difficulties the person was having.

For hospital-based staff, unexpected consequences of CST were that OTs and SLTs involved were able to assess people's ability to move and walk, for example, from a bed to a chair or to walk along a corridor, or their ability to communicate in a more naturalistic way, which proved to be more person-centred and less mechanistic than completing standardised transfer or communication checks as standalone assessments. Having gotten to '*know*' the person, staff found that they were able to make a better and more meaningful contribution when the person's progress or hospital discharge was being discussed at MDT meetings.

Almost two-thirds (64.2%) of participants agreed that they had some say in the activities of the group, and while this was a majority, this statement received by far the lowest percentage of positive responses. Getting input from participants into CST is a challenge as the intervention is delivered according to an evidence-based format. The intervention providers need time to prepare materials, and this places limits on participants having some say in the activities.

In interviews, grantees reported that a question frequently raised by participants at the end of the intervention was '*what next?*' One grantee reported that the group participants '*wanted a reunion when it was over*'. Several people with dementia commented on the evaluation form that they would like the CST intervention to continue or be extended or have an opportunity to take part in it again: '*Would like to participate again if it happened here*'.

Most projects reported that apart from day care centres, ASI social groups and Alzheimer Café's, there were few other psychosocial supports available for people with dementia in their area. While some projects implementing CST were linking group participants into existing day care centres or ASI social groups after the intervention came to an end, one project had opted to establish a peer support group for people with dementia in an effort to broaden the supports available and meet the expressed needs of people with dementia.

Hospital staff implementing CST to in-patients in the hospital noted that the intervention could end abruptly when people with dementia were discharged home. Having seen the positive impact for in-patients, they believed that CST would be of value to people with dementia following discharge home from hospital, but found that there was a dearth of CST in the local area. As a consequence, talks had been initiated with community-based health professionals and services to explore the possibility of setting up community-based CST groups in the vicinity of the hospital.

While most projects saw CST as a standalone intervention, one project saw CST as a mechanism for connecting with people with dementia and their family carers. The intervention allowed health professionals build-up relationships with people with dementia and their family members. As people with dementia, and family members especially, got to know and trust the staff through interventions such as CST, they would come to them either in person or by telephone with their everyday challenges and ethical dilemmas, and staff were available to offer advice and help them work through the issues and dilemmas and decide on the best course of action. The staff always encouraged the person and family to come back with feedback on how they got on, which was an important part of '*seeing things through*'. They viewed relationship building, advice and supporting people to work through problems as being very important and emphasised that '*the intervention does not begin and end with CST. It is much more than that. It is an integrated part of the work that we do.*' With grant funding, this project had tested the feasibility of delivering CST and determined the level of demand for it. Their next step was to look at addressing other support gaps that they had identified including the great need for support among family carers, the need for social occupation among people with dementia and the need for CR.

## 6.2 Cognitive Rehabilitation

Of the participants in CR interventions, 71 (88.8%) people with dementia completed evaluation forms, 56 of whom participated in group CR interventions and 15 in individual CR interventions. More than 90% of respondents rated the CR programme positively across all of the questions/statements in the evaluation form. This reached 100% for about half of the statements (See Appendix B, Table B.2). The positive responses to the CR interventions were reflected in the comments from people with dementia on the evaluation forms, with interventions described using words such 'very good', 'excellent', 'impressive', and 'enjoyable'.

The interviews with grantees and comments from participants shed more light on the mechanisms by which memory rehabilitation interventions generate benefits for people with dementia. One project explained that following a diagnosis, people with dementia and their family carers are often told that they can live well with dementia and are advised to make lifestyle changes or adopt strategies to help them do so, but they are rarely given guidance on how to put this advice into practice. Memory rehabilitation works by providing guidance on the different ways to make adjustments and different strategies that can be adopted, and introduces ways of reinforcing these adjustments. Many of participants commented on the practical information and advice, and useful tips that they had been given and the strategies that they had learned, and how this was helping them to manage everyday tasks:

***“An excellent programme which explained a lot and provided a lot of useful tips and ideas to make daily tasks a bit easier.”***

***“I have learned new ways of dealing with my memory problems and I try to write everything down.”***

A couple of people mentioned a specific goal that they had achieved or an action that had been taken as a result of participating in the intervention such as 'I'm back knitting because of the group' and 'It also reminded me to look at things for the future and since I have completed my Enduring Power of Attorney'.

Grantees expected participation in CR to address issues around confidence experienced by people following a dementia diagnosis. For some people, receiving a diagnosis can knock the person's confidence and by showing people what they can do to keep themselves well the intervention is believed to help build people's confidence back up again. Other people following a diagnosis can be overly confident about what they can do, but can quickly become overwhelmed or burnt out when confronted with the unpleasant realities associated with dementia. CR was expected to help people manage this. The vast majority of people with dementia agreed that 'I feel more confident in my ability to carry out daily routine activities', but a small number did not.

Most of the CR interventions used a group format, which was deemed necessary by some projects due to a lack of resources to offer a CR intervention on an individual basis. However, the projects highlighted the importance of the group setting, especially its role in offering peer support, which was seen to have a number of benefits. It allows people recently diagnosed with dementia to meet and be in contact with other people in similar circumstances. It allows people with dementia share information with each other, who, because of their shared experiences, were able to empathise with each other. People in the group are also able to offer each other reassurance. Hearing from others about how they are dealing with the diagnosis, especially from those who are open to it, can help people accept that the difficulties they are having. In this way, the group setting can help to challenge the stigma associated with dementia. Grantees described the rapport among participants as very good and said that bonds between people with dementia and family carers in the group has been formed. All people with dementia in group CR who completed an evaluation form liked the atmosphere in the group and agreed that the people in the group supported each other. The value of the group setting was encapsulated in the following comment made by one person with dementia:

***“Superb programme. I enjoyed the group setting as people were able to take strength from each other. I felt hopeless before coming to the group and the group has given me hope and a brighter future.”***

Building on the success of the peer support element of the CR intervention, one project formed a peer support group which participants could attend after completing the intervention. Access to support from health professionals was suggested by grantees to be another important mechanism by which the CR intervention helped people recently diagnosed feel supported, as it could lead to an increased sense of security and reduce feelings of anxiety and isolation. Several people with dementia commented on how reassuring this support was: *'It is very reassuring to know that there is support out there'*; *'Reassurance that there is support - feeling supported and reassurance that they are not on their own'*. This support was not something that people always expected: *'I can't believe that we got all this help and support for free in our own home.'* Grantees also felt that access to health professionals following a diagnosis is important as it gives people with dementia an initial contact with a key health professional and health service and that once good relationships with health professionals were established early on, these could be maintained and built upon throughout the dementia trajectory.

Some people stated that a four-week group CR intervention was not long enough - *'I enjoyed the group. The facilitators were very good and explained everything very well... would like the course to be longer'* - and others would like to do a refresher course: *'I would be interested in coming back for a refresher session. Enjoyed group and meeting new people'*.

Like the CST groups, an issue raised in the CR groups was what happens after the intervention ends. Grantees reported that some participants had arranged to meet again after the intervention ended either informally or by attending other group supports such as an Alzheimer Café together. It was believed that participating in the CR group gave people an opportunity to expand their social network and the confidence to start to use the community supports that are available. Grantees from one primary care project noted that having a social worker on the team would be highly valuable for finding out what is available in the community and connecting people in with groups and activities that are of interest to them. This is akin to the community connector role in the community supports model (Genio, 2016a) developed through the HSE & Genio Dementia Programme (Genio, 2016b).

### **6.3 Psychoeducational interventions**

With respect to the PE interventions, 39 (61.9%) people with dementia completed an outcomes evaluation form, the majority (n=31) of whom participated in individual dyadic interventions. Seven had participated in group dyadic interventions, and one person in an individual intervention for persons with dementia only. The vast majority of respondents answered all items on the form, but a few people chose not to respond to all items.

Responses by people with dementia to the PE interventions were very positive (see Appendix B, Tables B3). More than 90% of respondents rated the PE interventions positively across nearly all of the questions/statements in the evaluation form. 'I feel more positive about dementia' is the only statement to which less than 90% of people with dementia responded positively, but this was still a majority of 84%. A comment from one participant suggests that some people with dementia may be experiencing difficulty coming to terms with the diagnosis: *'I wish I didn't have the diagnosis and need the service of the programme'*. This may be an indication that individual counselling may be needed for some people post-diagnosis. In interviews with grantees, the lack of counselling services for people with dementia was identified by one CST group facilitator as a gap in post-diagnostic services, a gap that had become more apparent in running the CST intervention.

Of the 39 people with dementia who responded, 25 added a comment. Most of the comments related to an individual dyadic PE intervention that was provided in a day hospital setting. People with dementia described it as 'very good' and 'very helpful'. People stated that they had a better understanding or perspective of dementia as a result of the intervention, and several commented on the relaxed and calm atmosphere and lack of tension at sessions. The small number of comments on the other PE interventions were generally positive. One person attending a group intervention for people with young onset dementia commented that 'services and supports after the programme would be of help'.

A total 61 family carers (80.3%) on the PE interventions completed the outcomes evaluation form, 29 of whom participated in group interventions and 32 in individual interventions. Responses from family carers to the PE interventions were extremely positive (see Appendix B, Tables B4). Of the 61 family carers responding, 46 included a comment. Overall, comments by family carers were very positive. They described the interventions as 'very good' and 'excellent'. They found the information and advice offered to be valuable to them as family carers. They valued the opportunity to share their experiences with health professionals or with other family carers. They appreciated getting support and knowing that they are not alone. However, additional supports were not available to everyone.

***“Great programme, someone to talk to about things. Timing about right. [Health] professionals very helpful. Home help is greatest thing now that I have accepted them. Speaking out to others more.”***

***“[PE intervention] opened up a lot of doors to services we didn't know about. Unfortunately, there are lots of long waiting lists. Community needs to be resourced to provide services when required. No time to wait at this time” (Family carer of person with dementia).***

In addition to delivering a PE intervention, one project also developed a befriending service to address a service gap. Three people with dementia and about one-quarter of family carers expressed their gratitude at having an opportunity to share their experiences, being listened to and being understood, and mentioned the relief that they felt afterwards:

***“The nurses know what they are doing. I think it was brilliant. The calmness, reassuring, I looked forward to coming to meetings. Calmness went on a good bit after the meeting. For the first time someone believed and understood.” (Person with dementia).***

***“Invaluable programme to my Dad and me. My Dad has felt listened to for the first time and understands things from his perspective.” (Family carer).***

Reports by people with dementia and family carers that they are being listened to, being heard and understood is an indication of the provision of empathetic care. Empathy can be defined as 'understanding, sharing and creating an internal space to accept the other person, hence helping them to feel understood and not alone' and has been described as a necessary component of all caring relationships (Digby et al., 2016). Adopting an empathetic stance can be a means of socially acknowledging what people with dementia and family carers may be going through following a diagnosis of dementia, and can help to establish the ground for meaningful communication (McEvoy and Plant, 2014). Health care professionals who are empathetic will more easily develop a good rapport with people with dementia and their family carers. It is likely that people with dementia who receive empathetic care and feel heard will feel safe and will more readily accept support (Silverberg, 2006).

## 7. Discussion

A key aim of the NDO's Post-diagnostic Support Grant Scheme is to develop a pathway of care for people with dementia and appropriate interventions along the way. To this end, it grant-funded 18 projects to deliver at least one of three types of interventions, i.e. CST, CR and PE interventions. From our review and interviews with grantees, there was little in the way of PDS interventions in most project areas for people with dementia following a diagnosis of dementia prior to the NDO's PDS Grant Scheme. Specific interventions such as CST and CR were few and far between and available PE interventions tended to be targeted at family carers of people with dementia, and were not designed specifically for the post-diagnostic stage.

### 7.1 How resources were used

NDO funding provided an impetus for the implementation of CST, CR and PE interventions. Many of the health professionals leading and implementing interventions in the funded projects had previously recognised that there was a gap in post-diagnostic supports. While some projects were largely starting from scratch when funding was awarded, quite a number had already embarked on identifying PDS interventions to address the gap in meeting the identified needs of people with dementia in their area. Some had already gone so far as to get intervention training, to develop intervention content and materials, or seek input from people with dementia, and some had piloted an intervention and revised it following evaluation and feedback. Others had previously tried to deliver an intervention, but found that within existing resources and without dedicated time, they could only manage to deliver the intervention on an ad hoc and sporadic basis, or stream line the intervention to fit in with existing service provision. The funding, therefore, was crucial for enabling health professionals to introduce and deliver PDS interventions that they believed would enhance service provision and supports for people with dementia and their family carers, and to establish these on a firmer and consistent footing.

The grant funding could only be used for staffing, and this worked well when a senior health professional within the organisation (or service division) was identified and the funding used either to extend the number of days this staff member worked, or to allocate dedicated time for the staff member to work on the project and use the funding to backfill their post. Using the funding to recruit new staff or contract staff from different divisions of an organisation, either at senior or assistant level, was less successful, as projects had difficulty identifying people, and because the funding was 'non-standard', experienced long delays as a result of protracted and complicated recruitment processes. Some project could not secure approval to recruit staff. Recruitment was particularly challenging for projects based in primary care services. There is significant learning here in terms of internal recruitment processes which seem to be implemented in different ways in different service divisions and different areas, clarity around processes could overcome some barriers.

### 7.2 Interventions implemented

The projects could choose to implement at least one of three different interventions types: CST, CR and PE interventions, and each interview type is discussed next in turn.



### 7.2.1. CST interventions

The adoption of the UCL Making a Difference Programme by six of the projects is an indication of the acceptability of CST among service providers and senior health professionals in Ireland. Its adoption also brings to the fore the advantages for service providers planning on delivering CST to people with dementia. CST is underpinned by a robust evidence base and is strongly endorsed internationally. A well-defined CST intervention, the UCL Making A Difference CST programme, has been developed for adoption. A comprehensive training manual and DVD on how to offer the programme have been produced to support replication and implementation in practice (Streater et al., 2017). The intervention is targeted at one beneficiary group, i.e. people with mild to moderate dementia. CogsClub, an extended day-long version of the programme, has been developed for provision to people with dementia attending day care. The acceptability of CST in Ireland is consistent with findings from a study in the UK, which found that, as a post-diagnostic intervention, CST makes sense to staff in dementia care services, both those delivering CST and those managing staff where CST is delivered, and is seen to fit in with service goals of providing psychosocial support to people with dementia (Dickinson et al., 2017).

The cultural differences between the UK and Ireland are largely inconsequential when compared with the linguistic and cultural differences between the UK and other countries that have adopted CST such as India, Tanzania and Japan (Aguirre et al., 2014). Even so, all of the projects made changes to the intervention format and within thematic sessions. Intervention adaptation and fidelity are intrinsically linked and one of the main debates in the translation of evidenced-based interventions into practice, from an implementation science perspective, surrounds the degree to which an intervention is implemented as intended by the intervention developers (Perez et al., 2016). With respect to CST, guidelines have been developed to guide the adaptation of CST to different cultures and contexts in a way that does not compromise effectiveness and these have been used in other countries (Aguirre et al., 2014). However, the guidelines use a highly structured and programmatic five-step approach to adaptation, which requires time and resources, and is not always feasible for projects implementing CST with time and resource constraints such as those in the NDO's PDS Grant Scheme. From a complexity science perspective, in conditions of complexity, it is to be expected that interventions will be modified, sometimes extensively, as they are taken up in different contexts and settings (Greenhalgh and Papoutsis, 2019).

The CST intervention is worth scaling up in Ireland, but without a detailed evaluation of the adaptations made to existing models, it is difficult to be prescriptive on what works best for whom and in what circumstances. In addition, the impact of specific changes on the efficacy of CST needs to be considered. For example, many of the projects reordered the way in which the 14 sessions were delivered, often in a way that echoes changes made to the CST format elsewhere, and while findings from studies examining the efficacy of such changes is inconsistent, such changes may be justified for practical reasons such as time, resources and participant availability. However, more fundamental changes to the intervention such as reducing the number of sessions from 14 to 8 will likely compromise intervention effectiveness, and are not to be recommended. If these interventions are to be scaled up, further work is needed to ensure that there is a certain level of uniformity and consistency between CST interventions on offer in Ireland and the original models.

The evaluation has shown that it is feasible to provide CST to in-patients with dementia in an acute hospital setting, especially in the context of long in-patient stays. There is little in the way of activity or rehabilitation on offer for people with dementia in hospitals, and the implementation of CST in a hospital setting has highlighted the potential for 'activation' for people with dementia, which is known to be beneficial. However, consistent with findings from the UK (McAuley and Streater, 2019), implementing CST in an acute hospital presents particular limitations such as weekly changes in group size and people attending, and logistical challenges such as getting patients to and from the intervention. However, this inadvertently provided staff with an opportunity to observe people and identify the support needs they might have - in other

words positive, unintended consequences. Further issues highlighted by this evaluation are the level of diagnostic skills among staff within the hospital, the need for good recording of the diagnosis in patient records/case notes, the importance of creating a dementia-friendly environment and the importance of having dementia supportive staff at every level within the hospital. These are needed to support the optimal delivery of psychosocial interventions to in-patients with dementia. There is also much to be learned from earlier dementia hospital projects, such as DemPath and Cork-IDEASs, funded under the HSE & Genio Dementia Programme (Brady et al, 2018a; 2018b; 2018c).

CST training has been identified as important for supporting the implementation of CST. However, this evaluation has found that CST training in the form of single session training and the distribution of training manuals and DVDs may not, on its own, be sufficient to support implementation. Staff readiness and flexibility to implement an intervention are also important and these need to be assessed before plans are made to implement new interventions. Training strategies could also include expert consultation, and ongoing supervision, mentoring and consultation and feedback is needed for less experienced staff. Training to develop the adaptive capacity of staff may also be needed.

A large amount of time was invested by staff on the projects to source, collate and build up a bank of suitable, culturally relevant materials for CST, and sharing these materials among projects and making them available generally to health professionals or services planning to implement interventions would likely be time and cost saving. This is something which could be explored and facilitated centrally to support any future scaling up.

The target beneficiaries for CST are usually people with mild and moderate dementia, as evidence suggests that CST is an effective intervention for people at these stages of dementia. However, some of the projects opened the intervention up to people at a more advanced stage of dementia, and although there is no evidence on the effectiveness for people with severe dementia, project staff were of the view that these people were also benefitting from CST. A key issue that projects had to consider when forming CST groups was how the people in the group would interact, and stage of dementia was one way of gauging this, but organising groups to maximise interaction was only possible if there were a steady stream of referrals to the intervention.

### **7.2.2 CR interventions**

Currently, the best available evidence on effectiveness of CR relates to individual, goal-oriented CR. However, the projects funded tended to opt for memory rehabilitation, which is a more structured form of CR. An example is HBMR, which, although customised to individuals, places a greater emphasis on strategies than on individual goals. Although the evidence base is still limited, HBMR seems to have found favour in Northern Ireland and Scotland, especially among OTs. Ireland appears to be following this approach. The provision of Master Classes on HBMR, and the advice and support offered to the projects by specialist OTs is likely to have played a part in the projects' inclination towards memory rehabilitation. HBMR is provided on an individual basis to people in their own homes, but many of the projects chose to offer memory rehabilitation as a group intervention, as it includes an element of peer support, which project staff felt was important, but also because it is less resource intensive, as staff are not required to travel to people's homes. Resource issues also arose in relation to memory aids used to augment CR, which some projects could not offer due to financial constraints. However, this could be overcome to some extent when CR was delivered in MTRRs or rooms situated close to an ADL suite, where health professionals could demonstrate different products and devices that can be used as environmental prompts to support cognitive functioning. This represents a potential good use of the MTRR resource and could present options to other services.

Cognitive rehabilitation has the potential to be a valuable intervention, especially for people in the early stages of cognitive impairment who still have the ability to retain or learn new information and it is encouraging to see that the vast majority of people with dementia taking part in the CR interventions had been diagnosed with the past two years and almost three-quarters were people with mild dementia. The CR interventions are therefore largely reaching the intended target beneficiaries.

### 7.2.3 PE interventions

The PE interventions were the most heterogeneous of the three intervention types. Without a detailed evaluation of the various PE interventions, it is difficult to comment on the key components of the interventions and what works best for whom and in what circumstances. To date, PE interventions in Ireland have mainly been designed for family caregivers as the target beneficiary, but under the PDS Grant Scheme, all but one of the projects developed dyadic PE interventions. This, as far as we are aware, is a new departure in Ireland. The Next Steps Guidance on Psychoeducational interventions defines dyadic PE interventions as 'interventions where a person with dementia and their care partner attend joint group interventions' (Gibb et al, 2019). However, in terms of recruitment and take-up, the most successful PE intervention in the PDS programme was an individual, dyadic PE intervention, which involved a health professional meeting with a dyad (person with dementia and their family member) in a joint session which took place in a day hospital setting, once weekly over a period of up to four weeks. Another individual, dyadic PE intervention involved two health professionals meeting with the dyad in joint and separate sessions in the person's own home. This intervention also experienced some success. However, covering large geographical, mainly rural, areas to provide the intervention in people's homes was logistically challenging and resource-intensive in terms of staff time and travel costs.

Less successful in terms of recruitment and delivery were the dyadic group PE interventions. The number of people with dementia and family carers participating in group dyadic PE interventions was extremely low. This was due in part to delays in recruitment of staff. It was also linked to difficulties recruiting dyads experienced by three projects, which reported reluctance on the part of people with dementia and their family carers to join dyadic, group PE interventions. One explanation for this may be fear of disclosing a diagnosis to others in a group because of the stigma associated with dementia. Therefore, an important step before offering group PE interventions to people post-diagnosis may be supporting the person to talk about their dementia according to their preferences and needs. Another reason for low take-up was that some projects opted to develop new PE interventions from scratch. This is a really significant undertaking in terms of time and resources and requires a good deal of expertise. When time is taken to develop a new intervention, this is at the expense of intervention implementation and delivery. Future implementation of PDS interventions should carefully consider whether this is an acceptable use of resources considering the effort and resource involved and the availability of tried and tested interventions.

## 7.3 Staff roles and competencies

This evaluation has shown that health professionals delivering PDS interventions to people with dementia can be drawn from a range of disciplinary backgrounds. It has also identified the competencies that appear key for health professionals delivering CST, CR and PE interventions. The delivery of PDS interventions requires a workforce that are adequately trained and skilled not only in delivering the intervention but also to have the adaptive capacity to implement PDS interventions. While the skills of the health professionals delivering PDS interventions are important, the skills and commitment of projects leads, project managers and clinical supervisors are equally important. Implementation cannot be achieved by individual health professionals working in isolation. It requires team effort. Support from management is reinforcing and enabling, and therefore crucial. A positive by-product of the overall programme is that there is now a cohort of experienced health professionals in Ireland who can provide mentoring and support to other projects delivering psychosocial interventions in Ireland.

Implementing PDS interventions takes work, and usually involves health professionals investing time in a multitude of tasks and activities including adapting an existing intervention to the local setting and context, informing and educating other staff within and outside of the organisation about the intervention, building relationships and networks with other health professionals and services to facilitate and encourage referrals, identifying and developing referral pathways, assessing and selecting participants, identifying suitable venues for group interventions, and administration. The time taken to implement PDS interventions and engage stakeholders is considerable and should not be underestimated. Timelines for implementing can be compressed when staff are highly experienced and skilled at the tasks and activities involved, or alternatively, are closely supervised by staff highly experienced and skilled at doing this. However, a longer timeline may be needed when PDS interventions are being implemented for the first time by staff inexperienced at intervention implementation. Now that there is a cohort of experienced personnel around the country, there is potential for these staff to undertake support and mentoring of others who may not be as experienced, if these interventions are to be scaled up.

Collaboration with and support from health professionals working within and outside of the project team's organisation is vital for the successful implementation of PDS interventions. Project teams that had good networks and relationships with other health professionals and services in the local area were able to use this embeddedness to their advantage.

A total of 232 people with dementia participated in the PDS interventions between 1 January and 30 June 2019, 89 in CST, 80 in CR and 63 in PE interventions. A total of 140 family carers of people with dementia participated, 64 of whom attended CR with their relative and 76 family carers participated in PE interventions. These overall figures mask the wide-ranging levels of participation among the 19 interventions. A confluence of staff experience, skills, readiness and know-how, choice of intervention and decisions around adopting an existing intervention or developing a new one, embeddedness of staff within their own organisation and wider health system locally and management support all influenced the number of people who could avail of the PDS interventions. The local context including the level of demand and interest among people with dementia was very important.

The higher number of women than men participating in the interventions is to be expected as there is a higher prevalence of dementia among women. However, the small number of people with younger onset dementia may reflect the fact that the overall number of people with younger onset dementia in the country is relatively low and geographically they are widely dispersed. It could be that their support needs differ considerably from those of older people with dementia, or be related to the specific barriers that people with younger onset dementia face in accessing services generally such as perceived need or referral mechanisms. It could possibly reflect discrimination or higher levels of stigma experienced by people with younger onset dementia. The varying education levels among participants highlights the need to tailor psychosocial interventions accordingly. More than one in five participants with dementia were living alone, which is consistent with findings from other Irish studies on people with dementia (Keogh et al., 2018), and the chance to meet with other people through CST or CR groups may be particularly important to them.

#### **7.4 Recruitment and referral**

Much time was invested by the projects in recruiting people with dementia and family carers to the interventions. The numbers recruited by projects could be used as an indication of demand for the intervention in an area. However, a range of other factors also came into play such as the project team's pre-existing networks and relationships, links with local diagnostic services, recruitment strategies and quality of referrals. Staff recruitment difficulties, stigma associated with dementia and stage of intervention development also played a role.

As post-diagnostic supports, the diagnostic process is highly relevant to CST, CR and PE interventions. The evaluation has highlighted several pertinent questions and issues relating to diagnosis. Since the interventions tended to work well when staff implementing them were closely linked with memory clinics or those diagnosing dementia, should health professionals delivering PDS interventions be directly linked in with diagnostic services? If not, what referral pathways from diagnostic services to services delivering PDS interventions should be developed and how? If PDS interventions are to be offered on a planned basis and in a timely manner, who is best placed to assess a person's suitability for an intervention and discuss the options available with them? As well as needing to know if a formal diagnosis has been made, health professionals delivering PDS interventions need to know if the diagnosis has been disclosed to the person and be assured that a diagnostic disclosure has been made well. A dementia diagnosis can impact people differently and staff need to be aware of this. How should this, and issues such as stigma, and lack of insight be addressed, and should these be left solely to health professionals delivering PDS interventions to address? Again, those working closely with personnel or services involved in diagnosis found this easier, though still challenging.

### **7.5 Family carers**

Family carers often attended CR with their relative and participated in PE interventions with their relative or separately. Families were also involved in the CST interventions, as most people with dementia who travelled to get to CST groups, as well as the other PDS interventions, relied on a family member or friend to drive them to the venue and home afterwards. Thus, a level of commitment from family carers for PDS interventions to run successful, signalling the important role that families play. However, some people referred to interventions could not participate because they did not have someone to give them a lift to the venue. While on average travel time was approximately 15 minutes to get to venues, some people were willing to travel substantial distances to participate in interventions. Efforts were made by some projects to minimise journey lengths by bringing the intervention to venues closer to where participants lived, but this takes work and was not always successful. Access issues were not confined to getting to and from a venue, but continued at the venue and included issues such as parking and wayfinding, and the importance of staff working within buildings where PDS interventions are held having an understanding of dementia, and providing support to the project staff and participants has been highlighted by this evaluation.

### **7.6 What people with dementia valued about the interventions**

There is an established and growing evidence-base for CST, CR and, to a lesser extent, PE interventions. Further to that, the overwhelming majority of people with dementia who participated in the CST, CR and PE interventions in the PDS programme and completed an evaluation form rated these interventions very positively. It is clear that the interventions were of value to those that participated directly and their families. Those providing the interventions also reported significant value added, not only for recipients, but also in relation to overall care objectives including staff morale and satisfaction.

CST participants welcomed the opportunity for social interaction and the chance to 'talk'. They enjoyed the sessions especially when there was laughter and fun. The peer support offered by CST groups was important, and made participants feel that they are not alone. CST also has the potential to make people with dementia feel valuable, in the sense of still being able to make a contribution. There were also benefits for staff. CST is a person-centred approach, and the sessions can allow staff get to know each person behind the dementia, and also unobtrusively assess their support needs. People with dementia were disappointed when the groups came to an end, as there were so few other support options available for people. This led one project to form a peer support group which participants could attend. Maintenance CST, which has shown to be effective, is potentially another option to facilitate additional support.

People participating in the CR interventions found the information and advice received at the sessions practical. They found the tips and strategies helpful to them in managing everyday tasks and most agreed that the intervention gave them more confidence in doing this. With respect to the group interventions, peer support was identified by staff as an important element, and this seems to be backed up by the responses and comments of participants. Participants also valued the reassurance they got from being connected with health services staff and knowing that there is someone there to support them. For staff, it was important to be able to link in with people with dementia and their family carers soon after the diagnosis and use this initial contact as a platform for building relationships at an early stage rather than having to do so much later in the disease trajectory.

Most of the feedback from people with dementia participating in PE interventions related to individual dyadic interventions and they rated these positively. Family carers participating in PE interventions also rated these positively. Receiving information, advice and a better understanding of dementia was important to people. However, knowledgeable staff, a relaxed and calm atmosphere in which people with dementia and family members can talk about dementia, and be listened to and heard were also important aspects of this intervention, highlighting the importance of health professionals taking an empathetic stance in providing psychoeducational support to people with dementia and their family carers.

## 8. Conclusion

The NDO's Post-diagnostic Support Grant Scheme, using funding from Dormant Accounts, has enabled projects around the country to develop and test the implementation of CST, CR and PE interventions. Availability of these interventions had previously been low in Ireland. There is much learning for the HSE from the implementation of the PDS interventions. The evidence from the review suggests that additional resources should be made available to put psychosocial interventions on a firm and consistent footing within the dementia sector in Ireland.

Acceptability of CST internationally is high and the programme is worth scaling up in this country. More attention needs to be paid to adaptations of CST, and how this might impact on efficacy. In any future expansion there is need to ensure a certain level of uniformity and consistency between CST interventions in Ireland and with existing international models. While RCTs are considered the gold standard when assessing the effectiveness of an intervention, they are often not feasible nor worthwhile. One way of assessing whether CST is being delivered in accordance with the original model is to develop a checklist for health professionals to complete. The checklist approach has been used for the implementation of Maintenance CST (Orrell et al., 2014) and adopted for the implementation of CST in low and middle-income countries (Spector et al., 2019) and could be used in Ireland to demonstrate adherence to evidence-based international CST models and foster uniformity between CST interventions in Ireland.

CR has the potential to form a valuable component of PDS for people with dementia. Memory rehabilitation seems to be the preferred approach in Ireland, following the preferred model in Northern Ireland and Scotland. Both HBMR and group-based memory rehabilitation were evident in this review and each has advantages and disadvantages. The former facilitates health professionals to undertake individual CR with the person in the context of their home environment but travelling to people's homes is time-consuming and resource intensive. Within group work, individual interaction with participants is limited but advantages are that it uses less resources and enables an element of peer support.

There are significant benefits associated with PE interventions, and the need to tailor such interventions to people at the early stage of the care trajectory following a dementia diagnosis has been highlighted. The PE interventions developed and implemented under the PDS programme were heterogeneous in nature. There is a need for the development of more thorough descriptions of the PE interventions, perhaps using tools developed for this purpose, such as the TiDieR template (Hoffman et al., 2014). This would be of value to other health professionals seeking to implement and replicate the PE interventions. It would also aid future evaluation. While the international evidence on PE is not as strong as CR and CST, evidence from this evaluation adds to a limited body of knowledge in this regard.

While PE has traditionally been developed for family carers, it is notable that the majority of PE interventions as part of the scheme were dyadic. Of the dyadic PE interventions, those that were provided individually to people with dementia and their family carers were more successful with regard to recruitment and take-up than group dyadic interventions. Staff recruitment issues, stigma associated with dementia and time invested in developing new PE interventions all influenced the low take-up of group dyadic PE interventions.

PDS interventions can be delivered by health professionals from a range of disciplinary backgrounds who are trained and skilled in delivering the interventions. Implementing PDS interventions requires a dedicated and skilled team of health professionals possessing

implementation knowledge and experience of how to work with people with dementia. Support from management is crucial; so too is internal teamwork. Networking and collaboration with other staff both within and outside the organisation are essential. A positive outcome of the overall programme is that there is now a cohort of experienced health professionals in Ireland with the necessary experience and skills who can provide mentoring and support to other projects delivering and implementing psychosocial interventions in Ireland.

Over the six-month evaluation data collection period (Jan to June 2019), a total of 232 people with dementia and 140 family carers of people with dementia participated in and the PDS interventions. Levels of participation among the 19 interventions varied greatly, and while this could be taken as an indication of demand locally, it was influenced by a wide range of other factors including staff experience, skills, readiness and know-how; decisions relating to the intervention; embeddedness of staff within their own organisation and wider health system locally; management support; recruitment strategies and quality of referrals. The suitability of people for different PDS interventions types is a key learning of this evaluation. The evaluation has highlighted several pertinent questions and issues relating to diagnosis, which need consideration as these impinge directly on the delivery and implementation of PDS interventions. Before post-diagnostic supports comes diagnosis. Once a diagnosis has been made, there is an opportunity to guide people to post-diagnostic supports. This needs to be undertaken in negotiation with people with dementia and their family carers. However, a key question raised by this evaluation is who should be undertaking an assessment post-diagnosis to ensure that people are appropriately referred, if that is their preference, to different PDS interventions. The timing of the PDS intervention is also vitally important, and individual needs, preferences and abilities need to be taken into account by staff to ensure that the intervention is offered at the right time. PDS interventions are time-limited, and this raises the perennial question of what happens for the person when the intervention comes to an end? Participation in a PDS intervention may in some cases serve as an entry point to other community-based services and supports, but this is dependent on the availability locally of appropriate post-diagnostic services, supports and interventions, and on the individual needs and preferences of people with dementia and their family carers.

There are several practical lessons to be learned from this evaluation. Facilitating groups of people with dementia, family carers or dyads is highly skilled work and for the optimal delivery of PDS interventions, staff need to have excellent group facilitation skills. It is important to deliver PDS interventions for people with dementia and family carers in appropriate venues. However, it can be challenging for staff to source suitable venues and can take up valuable time. To access PDS interventions, people with dementia need to get to venues where group PDS interventions are held, and family carers play a large role in this. Holding interventions close to where participants live reduces the amount of time people have to spend travelling to and from the intervention. Accessibility of the venue, parking and transport links, are important, but access does not end with transport to and from a venue. Once at the building, people with dementia and family carers can face other access issues relating to getting into, around and out of buildings. Staff need to be aware of these barriers and develop strategies to address them. It is important that buildings are designed to be dementia-inclusive, but also that staff in buildings are dementia aware and supportive. The room itself is important, and the optimal delivery of a PDS intervention can be compromised where a room is not fit for purpose. Staff implementing PDS interventions can spend a large amount of time sourcing, collating and building up a bank of suitable materials and resources, and there are likely to be time and cost savings to be made from the sharing of these among health professionals and services.



It is increasingly recognised internationally that people with dementia can benefit from post-diagnostic supports following a diagnosis of dementia. The findings and unique insights from this evaluation offer Irish evidence from the real-world implementation of three types of psychosocial interventions. The overwhelming majority of people with dementia who participated in the CST, CR and PE interventions in the PDS programme and completed an evaluation form rated these interventions extremely positively. The PDS interventions also had a positive impact on staff. Through the delivery of interventions that adopt a person-centred approach and focus on reablement, staff were able to get to see and appreciate the person and their capabilities. These findings suggest that PDS interventions have the potential to be a valuable addition to the dementia landscape.

Additional resources will be necessary if these interventions are to be scaled up and placed onto a firm and consistent footing. The evidence from this review is that there will be a significant return from any new investment in this area for people with dementia, their family carers, formal care providers and wider society.

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## Appendix A

### Participants in PDS interventions (Sept 2018 to Aug 2019)

A total of 419 people with dementia participated in the PDS interventions between September 2018 and end of August 2019 (Table A1). This figure includes people with dementia who completed an intervention and those who had enrolled on an intervention that was still in progress at the end of August 2019.

**Table A1: Participation of people with dementia in PDS interventions (September 2018 to August 2019)**

	No. of people with dementia <sup>1</sup>	No. of projects	Average per project	Range
CST	184	7	26.3	7-72
CR	130	6	21.7	10-40
PEP	105	7	15.0	2-61
<b>Total</b>	<b>419</b>	<b>19</b>	<b>22.1</b>	<b>2-72</b>

<sup>1</sup>Includes people with suspected dementia but no formal diagnosis

In addition, 218 family carers of people with dementia attended PDS interventions (Table A2).

**Table A2: Participation of family carers of people with dementia in PDS interventions (September 2018 to August 2019)**

	No. of family carers	No. of projects	Average per project	Range
CR	95	6	15.8	8-24
PEP	123	7	17.6	2-59
<b>Total</b>	<b>218</b>	<b>13</b>	<b>16.8</b>	<b>2-59</b>

Over the period September 2018 to August 2019, 184 people with dementia attended CST interventions delivered by seven projects. This gave a project average of 26.3. However, some projects were more successful at delivering the intervention than others and the number of people with dementia attending varied greatly amongst projects from 7 to 72 (Table A1).

For CR interventions, 130 people with dementia attended delivered by six projects, averaging at 21.7 per project, but ranging from 10 to 40 (Table A1). 95 family carers of people with dementia attended CR interventions.

A total of 105 people with dementia attended PE interventions delivered by seven projects, averaging at 15 per project, and ranging from 2 to 61 (Table A1). A total of 123 family carers of people with dementia participated in PE interventions (Table A2).

In addition to people with dementia, 34 people without dementia (e.g. people with Mild Cognitive Impairment) participated in CST and CR, and five family carers attended CR with their relative. Table A3 presents shows figures on all participants in PDS interventions between September 2018 and August 2019.



Table A3: All participants of PDS interventions September 2018 to August 2019

Intervention type	People with dementia <sup>1</sup> (N)	People without dementia (N)	Family carers attending with people with dementia (N)	Family carers attending with people without dementia (N)	Total (N)
CST	184	21	-	-	205
CR	130	13	95	5	243
PEP	105	-	123	-	228
<b>Total</b>	<b>419</b>	<b>34</b>	<b>218</b>	<b>5</b>	<b>676</b>

<sup>1</sup>Includes people with suspected dementia but no formal diagnosis

# Appendix B

## Responses of participants to PDS interventions

**Table B1: Responses of people with dementia to CST intervention**

Q		Yes n (%)	No n (%)	Prefer not to say n (%)
01	Overall, did you find taking part in the programme was of value to you? (n=67)	65 (97.0)	0 (0.0)	2 (3.0%)
02	People in the group took time to talk to me and listen to me (n=67)	65 (97.0)	0 (0.0)	2 (3.0%)
03	I felt safe expressing my opinions in the groups. (n=67)	64 (95.5)	1 (1.5)	2 (3.0)
04	I can be myself here. (n=67)	67 (100.0)	0 (0.0)	0 (0.0)
05	I have some say in the activities of the group. (n=67)	43 (64.2)	18 (26.9)	6 (9.0)
06	Doing the activities gave me a sense of achievement. (n=67)	57 (85.1)	3 (4.5)	7 (10.4)
07	The group activities were relevant to my everyday needs. (n=67)	50 (74.6)	8 (11.9)	9 (13.4)
08	In this group, I had an opportunity to hear people's views. This broadened my outlook on life. (n=66)	61 (92.4)	2 (3.0)	3 (4.5)
09	I enjoyed the conversations and could talk easily in the group. (n=67)	64 (95.5)	0 (0.0)	3 (4.5)
10	The group is pleasant. I feel able to relax and enjoy attending the group / programme. (n=67)	66 (98.5)	0 (0.0)	1 (1.5)
11	Having completed the group, I now feel more comfortable talking about my memory problems / dementia (n=66)	47 (71.2)	5 (21.2)	14 (7.6)
12	I feel safe sharing difficulties or problems life throws at me with the group. (n=64)	48 (75.0)	4 (6.3)	12 (18.8)
13	I like the atmosphere in the group. (n=65)	63 (96.9)	2 (3.1)	0 (0.0)
14	The people in the group supported each other. (n=67)	65 (97.0)	1 (1.5)	1 (1.5)
15	The programme gave me an opportunity to meet people in a similar situation to me. This was of benefit to me. (n=67)	65 (97.0)	1 (1.5)	1 (1.5)
16	I enjoyed the activities. (n=66)	65 (98.5)	0 (0.0)	1 (1.5)
17	Would you recommend this programme to another person? (n=67)	64 (95.5)	1 (1.5)	2 (3.0)

Table B2: Responses of people with dementia to CR interventions

Q		Yes n (%)	No n (%)	Prefer not to say n (%)
01	Overall, did you find taking part in the programme was of value to you? (n=71)	70 (98.6)	1 (1.4)	0 (0.0)
02	The facilitator(s) took time to talk to me and listen to me (n=71)	71 (100.0)	0 (0.0)	0 (0.0)
03	I felt safe talking about my experiences and expressing needs. (n=71)	71 (100.0)	0 (0.0)	0 (0.0)
04	The programme was relevant to my circumstances and daily routine. (n=71)	68 (95.8)	1 (1.4)	2 (2.8)
05	I have a say in the goals identified and strategies developed for me. (n=70)	69 (98.6)	0 (0.0)	1 (1.4)
06	I have learned strategies for use in my daily routine (n=71)	70 (98.6)	1 (1.4)	0 (0.0)
07	The strategies I learned are practical and relevant to my daily needs. (n=70)	69 (98.6)	0 (0.0)	1 (1.4)
08	I put or intent to put the strategies I learned into practice in my daily routine. (n=69)	69 (100.0)	0 (0.0)	0 (0.0)
09	The strategies I have learned help my better manage my daily routine. (n=70)	70 (100.0)	0 (0.0)	0 (0.0)
10	I enjoyed attending the programme and learning practical strategies. (n=71)	71 (100.0)	0 (0.0)	0 (0.0)
11	Having completed the group, I now feel more comfortable talking about my memory problems / dementia (n=71)	66 (93.0)	3 (4.2)	2 (2.8)
12	I feel more confident in my ability to carry out daily routine activities. (n=69)	65 (94.2)	3 (4.2)	1 (1.4)
13	I like the atmosphere in the group. (n=56)	56 (100.0)	0 (0.00)	0 (0.0)
14	The people in the group supported each other. (n=56)	56 (100.0)	0 (0.00)	0 (0.0)
15	The programme gave me an opportunity to meet people in a similar situation to me. This was of benefit to me. (n=56)	56 (100.0)	0 (0.00)	0 (0.0)
16	I feel more positive in my everyday life. (n=71)	67 (94.4)	2 (2.8)	2 (2.8)
17	Would you recommend this programme to another person? (n=71)	70 (98.6)	1 (1.4)	0 (0.0)

Table B3: Responses from participants with dementia to psychoeducational interventions

Q		Yes n (%)	No n (%)	Prefer not to say n (%)
01	Overall, did you find taking part in the programme was of value to you? PwD: n=39	38 (97.4)	0 (0.0)	1 (2.6)
02	The facilitator(s) took time to talk to me and listen to me PwD: n=39	38 (97.4)	0 (0.0)	1 (2.6)
03	I felt safe talking about my experiences and expressing needs. PwD: n=38	37 (97.4)	1 (2.6)	0 (0.0)
04	The programme was relevant to my circumstances and daily routine. PwD: n=38	38 (100.0)	0 (0.0)	0 (0.0)
05	I had some say in the topics included in this programme. PwD: n=39	36 (92.3)	3 (7.7)	0 (0.0)
06	My knowledge about and understanding of dementia has increased. PwD: n=39	39 (100.0)	0 (0.0)	0 (0.0)
07	I am better able to plan for the future with dementia as a result of taking part in the programme. PwD: n=38	36 (94.7)	2 (5.3)	0 (0.0)
08	The programme included practical information and tips that I put or intend to put into practice in my daily routine. PwD: n=37	35 (94.6)	2 (5.4)	0 (0.0)
09	Having completed the programme, I am better able to accept my personal situation. PwD: n=38	36 (94.7)	2 (5.3)	0 (0.0)
10	I enjoyed taking part in the programme and learning about dementia and getting practical information. PwD: n=37	37 (100.0)	0 (0.0)	0 (0.0)
11	Having completed the group, I now feel more comfortable talking about my (or my relative's/friend's) memory problems / dementia PwD: n=38	36 (94.7)	2 (5.3)	0 (0.0)
12	My ability to cope and manage in everyday life has improved as a result of the programme. PwD: n=35	33 (94.3)	2 (5.7)	0 (0.0)
13	I like the atmosphere in the group. PwD: n=7	7 (100.0)	0 (0.0)	0 (0.0)
14	The people in the group supported each other. PwD: n=7	7 (100.0)	0 (0.0)	0 (0.0)
15	The programme gave me an opportunity to meet people in a similar situation to me. This was of benefit to me. PwD: n=7	7 (100.0)	0 (0.0)	0 (0.0)
16	I feel more positive about dementia. PwD: n=39	32 (82.1)	6 (15.4)	1 (2.6)
17	Would you recommend this programme to another person? PwD: n=39	38 (97.4)	0 (0.0)	1 (2.6)

Table A.4: Responses of family carers to psychoeducational interventions

Q		Yes n (%)	No n (%)	Prefer not to say n (%)
01	Overall, did you find taking part in the programme was of value to you? (PwD: n=39; FC: n=61)	61 (100.0)	0 (0.0)	0 (0.0)
02	The facilitator(s) took time to talk to me and listen to me (PwD: n=39; FC: n=61)	61 (100.0)	0 (0.0)	0 (0.0)
03	I felt safe talking about my experiences and expressing needs. (PwD: n=38; FC: n=61)	61 (100.0)	0 (0.0)	0 (0.0)
04	The programme was relevant to my circumstances and daily routine. (PwD: n=38; FC: n=61)	61 (100.0)	0 (0.0)	0 (0.0)
05	I had some say in the topics included in this programme. (PwD: n=39; FC: n=61)	58 (95.1)	2 (3.3)	1 (1.6)
06	My knowledge about and understanding of dementia has increased. (PwD: n=39; FC: n=60)	59 (98.3)	1 (2.7)	0 (0.0)
07	I am better able to plan for the future with dementia as a result of taking part in the programme. (PwD: n=38; FC: n=60)	58 (96.7)	1 (1.7)	1 (1.7)
08	The programme included practical information and tips that I put or intend to put into practice in my daily routine. (PwD: n=37; FC: n=60)	59 (98.3)	1 (1.7)	0 (0.0)
09	Having completed the programme, I am better able to accept my personal situation. (PwD: n=38; FC: n=60)	57 (95.0)	2 (3.3)	1 (1.7)
10	I enjoyed taking part in the programme and learning about dementia and getting practical information. (PwD: n=37; FC: n=60)	59 (98.3)	0 (0.0)	1 (1.7)
11	Having completed the group, I now feel more comfortable talking about my (or my relative's/friend's) memory problems / dementia (PwD: n=38; FC: n=58)	55 (94.8)	2 (3.4)	1 (1.7)
12	I feel more confident in my caregiving role. (PwD: n=35; FC: n=59)	56 (93.3)	3 (5.0)	1 (1.7)
13	I like the atmosphere in the group. (PwD: n=7; FC: n=28)	28 (100.0)	0 (0.0)	0 (0.0)
14	The people in the group supported each other. (PwD: n=7; FC: n=28)	28 (100.0)	0 (0.0)	0 (0.0)
15	The programme gave me an opportunity to meet people in a similar situation to me. This was of benefit to me. (PwD: n=7; FC: n=28)	27 (96.4.0)	0 (0.0)	1 (3.6)
16	I feel more positive about dementia. (PwD: n=39; FC: n=60)	53 (91.4)	4 (6.9)	1 (1.7)
17	Would you recommend this programme to another person? (PwD: n=39; FC: n=60)	60 (100.0)	0 (0.0)	0 (0.0)

