Developing Integrated Personalised Supports for People with Dementia

Part 3: Recommendations based on learning from the implementation of a programme accross eight sites in Ireland

Prepared by Elaine Howard, Anne Quinn and Ann-Marie Coen, Genio

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Health Service Executive

GENIO

Acknowledgements

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1.0 Executive Summary

There is general agreement that demand for health services is going to increase significantly in the next decade because of demographic and epidemiological trends. This requires careful consideration of capacity needs across the health and social care system as well as looking at available resources and how those resources are used. This is particularly relevant for people with dementia who will require considerable support as their condition progresses.

The Irish National Dementia Strategy 2014 (NDS) commits to caring for people with dementia in their own homes for as long as possible. The National Dementia Strategy Implementation Programme (NDSIP) has five priority action areas, one of which is the further development of integrated services for people with dementia – particularly home support. Under this action, the Health Service Executive (HSE), as part of its Intensive Home Care Package (IHCP) initiative, prioritised the roll-out of IHCPs for people with dementia in nine sites across Ireland over three years (2015-2017).

An evaluation and support arrangement was built into the NDSIP. Under a service level agreement with the HSE, Genio's role was to:

1. Support the HSE in the development of a suite of indicators for IHCPs and related data collection tool and provide on-going data analysis and reporting of IHCPs, with a focus on IHCPs for people with dementia. Report 1, titled *Supporting Older People with Complex Needs at Home: Evaluation of the HSE Intensive Home Care*

Package Initiative - Context, Recipients and Costs (Keogh et al 2018) which can be found here www.genio.ie/dementia-report1-ihcp.

2. Design, manage and undertake an in-depth study of a sample of dementia focused IHCPs to evaluate their effectiveness and how well they are working. The conduct and findings of this in-depth study are the subject of this Report 2, titled *Supporting Older People with Complex Needs at Home: What Works for People with Dementia?* (Keogh et al 2018) which can be found here www.genio.ie/dementia-report2-ihcp.

3. Support the HSE in the implementation of personalised dementia-IHCPs which is the content of this report 3 *Developing integrated, personalised supports for people with dementia: Recommendations based on learning from the implementation of a programme across eight pilot sites in Ireland* www.genio.ie/dementia-report3-personalised.

Following the publication of the NDS at the end of 2014, the HSE and The Atlantic Philanthropies jointly developed and invested in a programme aimed at supporting the implementation of the strategy.

The HSE commissioned Genio to undertake a pilot programme to explore the 'pathways and processes' aspects of Dementia-Specific Intensive Home Care Packages (DSIHCPs). This programme set out to identify the principal challenges and enablers for undertaking personalised care by testing the concept within real environments of care delivery. The HSE selected eight sites,

aligned to specific hospital catchment areas where multi-disciplinary, local staff teams could work together to develop integrated, personalised services.

> **The term "personalised"** as applied to supports in this report, is a broad term used to describe different ways to support people with dementia to maximise their abilities and enable them to remain living a full life. Such supports include the range of physical, personal and psychosocial needs that a person with dementia may have and gives equal weight to these support needs required by the person to have a full, meaningful life. A personalised approach to care is designed with the person with dementia and their primary carer.

This report studies this change programme piloted across the eight pre-selected sites across Ireland (see Appendix 1). The programme tailored homecare packages to suit the needs and preferences of individuals with dementia and to better integrate these supports across health and social care staff. The study is based on a rigorous, qualitative analysis of staff perceptions of:

1. The current context within which supports are provided to people living with dementia and their families.

2. The change process which they engaged in and the challenges and opportunities which they encountered as they sought to roll out a more personalised approach.

3. The benefits and challenges of implementing this more personalised, integrated approach.

4. The potential for widening the impact to HSE homecare supports more generally and the steps which should take place to support this to happen.

5. The implications for costs and how improvements can take place within the current funding envelope.

6. How the home care support system can adapt towards more personalised approaches.

Whereas reports on social service reform often describe "idealised" states for service to move towards, this programme of work emphasised incremental change which is achievable and practical. The journey which the staff engaged in as part of this work demonstrates that the personalisation and integration of health and social care supports is feasible if it is managed and facilitated appropriately. This report should be read in conjunction with the two accompanying studies (see page 4) which comprise the evaluation of the DSIHCP.

1.1   The Main Findings

A personalised approach to care delivery was tested within existing services. This demonstrated the potential for cost-effective outcomes that are quality-driven and facilitate the avoidance of premature entry to long-term care. Enhanced practices were developed, which addressed local challenges and engaged families as key supporting partners.

This section outlines the benefits and challenges of the roll-out of the work piloted

across the sites. Specific recommendations are also set out as to how the work of the pilots can be expanded across wider geographic areas and appropriate processes developed at a national level to facilitate this.

1.1.1 Current Context

The national rollout of the DSIHCPs was broadly welcomed by staff. There were, however, several significant challenges in the implementation of this national roll out. Staff felt that the current system of DSIHCP was unfair and that it was hard to justify the intensive funding of a limited number of cases against the background of waiting lists and scarcity for the majority. Staff identified the risk of needs being overestimated to access resources; and a fragmented, siloed approach to service provision, with the scope of supports limited to health and physical care needs. Internal communication within the health and social care systems was also highlighted as a significant challenge, with difficulties arising from uncertainty over availability, eligibility and notification regarding release of packages.

1.1.2 Potential to Change Ingrained Practices and Beliefs

During the pilot processes in the eight sites the staff worked on implementing personalised supports. While some staff had prior experience of approaches to personalising supports and integrating supports across disciplines, for many this was a relatively new way of working. The perceived limitations by many staff, of adopting a personalised approach to care for people with dementia, were based around the constraints of the current system. For example, the current system prioritises physical and personal care needs rather than being inclusive of, and giving equal weight to, the psychosocial needs of the person with dementia. This constraint led some staff to start the conversation with people with dementia and families from the point of view of 'this is what we can provide' instead of asking 'what are your needs?'. The groups welcomed having the space to engage in a rigorous, facilitated process to develop a realistic vision for developing and delivering supports tailored around the needs of individuals and their families. Having the staff from across disciplines work together as groups on 'real' cases was central to this progress. This grounded the change process in concrete examples. Whilst this change was incremental it was significant. Having completed the pilot programme and built capacity in personalised supports, staff felt that there was a significant amount of personalisation and integration that could take place, even within existing resource constraints.

1.1.3 Change from perceiving challenges as externally imposed constraints to exploring local solutions

Dialogues at the outset of the processes started with an articulation of the challenges and frustrations, particularly around resources. Grounding the work in specific examples, coupled with a facilitated change process, enabled changes to take place across silos, where integration and coordination of services were usually limited. There was also much greater engagement and co-design with people using services and their families.

1.1.4 Centrality of Families to Change

As highlighted in the first two reports in this evaluation series, the family members are generally the primary support providers for people with dementia, which is then supplemented by state support.

A successful outcome for the person with dementia was dependent on the inclusion of the person with dementia and their primary family carer in a process to identify needs and to design a personalised response. Seeing families as the lead partners in supporting people with dementia instead of 'problematic advocates for unavailable resources' was a significant development for staff.

During this process, staff found that when they engaged with families, built a relationship of trust and co-designed supports, they were able to maintain and strengthen this central pillar of homecare service in Ireland. Supporting families to continue in the significant role of primary carer took many forms including education, one-to-one support, and respite support that could be mutually beneficial to the person with dementia and their family.

Engaging families also meant supports could be tailored around the needs and preferences of the person with dementia.

This was viewed as being very different to the current wider homecare system, where family engagement is sometimes perceived as challenging, and at times is avoided or limited, due to uncertainty around criteria for support and lack of available resources The current system is also viewed by many staff as consisting of services siloed within disciplines resulting in fragmented approaches, time-based requests for support, and expensive, state-led responses to crises.

1.1.5 Management and Leadership of Change

Whereas this work had a dementia specific focus, the lessons are broadly transferable across other areas of health and social care homecare services.

While working group members broadly committed to actively contributing to any future programme in their area that could support a wider implementation of personalised supports, they clearly reflected the futility of such an approach without the commitment and engagement of the relevant national and local stakeholders to such a change programme.

Groups advocated for commitment from senior staff within the Community Healthcare Organisations (CHOs) of their pilot sites and from national senior management to support and augment any rollout of personalised supports to home care services more broadly. Groups recognised that such an approach requires the input and commitment of all levels of the system to support successful and standardised outcomes.

Particularly, there was demand for more local forums that would work towards integrating services and adapting personalised supports and local community connection. Training and development across the staff base for personalised working was advocated for in all pilot sites.

Additionally, a need was expressed for the development of national protocols for the delivery of personalised supports in home care. The inclusion and recognition of the psychosocial support needs that a person may have, was considered essential. Equal weight to psychosocial needs and the already recognised personal and physical needs that a person may have, was considered a necessary adjustment to home care services.

All sites asserted that HSE staff would not be in a position to support out-of-home support due to insurance concerns. Some felt that private providers undertaking work for the HSE could not bring people outside of the home while others did not see an issue with this, as they felt the providers' insurance covered any risks. The variance of approaches and uncertainty of scope among sites was considered unhelpful in achieving consistent and optimal services.

1.1.6 Greater Cost Effectiveness

Personalised, integrated homecare was considered by the working groups to have significant potential to optimise current resources and even reduce costs.

One participant reflected on how dementia was viewed by many of the participants, prior to engaging in the pilot programme.

"We've known for the last three to four years that dementia was becoming a significant part of the request for supports. We don't have the resources to dedicate fully to it because you'll just be swamped, we couldn't… WG1 M5#"

The early expectation was that implementing a personalised approach would be very

costly. This view changed once the approach had been tested and many described being surprised by how cost-effective it could be when supports are personalised to the individual. Many participants reflected that by co-designing supports with the person and their family, specific 'asks' were oftentimes less than expected. The following quotes from one working group share such learnings:

"It's a more appropriate ask for supports as opposed to inflated I think because its person centred so you're looking at what that person needs and wants…." (WG6 M5#)

"So not having that framework of you have 20 hours to spend how do you want them? As opposed to going in and saying well what do you need? The proof is in the pudding you know that would be one of the smaller DSIHCPs that we would have and certainly one of the least expensive and that was based on 'Well what do you want?'" (WG6 M5#)

Personalised approaches were live tested, and cases demonstrated improved hospital discharge, supported hospital avoidance, and supported premature long-term care avoidance; as well as keeping people living well at home.

This was reflected in cases at all stages of dementia and at various levels of complexity.

The process of personalising packages was seen as central to saving costs and maximising resources. Rather than having a standardised pre-determined format such as a 30-minute or one-hour allocation of support to provide personal care at set intervals during the day,

personalised packages could be 'goal focused' and agreed in cooperation with the person with dementia and their family.

The enhanced engagement with the supporting partners of family, wider social networks and wider community was also seen as a contributing factor to cost efficiencies as well as improved quality of supports where health and social care were only engaged to fill the remaining, identified gaps in support needs.

"I think that's the point we're making. If we did things differently, we would see much greater value, much greater quality and much greater levels of satisfaction actually." (WG2 M5#)

Participants asserted that the provision of DSIHCPs in the current form, without appropriate training and facilitation in the delivery of personalised supports, would not result in savings and could in fact increase costs. It was argued that the existing threshold entry points for DSIHCPs could mean that the starting point of consideration is a fixed number of hours and then how those hours might be delivered. A personalised approach differed, starting with the question 'What do you need?', and then co-designing supports with the person and their family that resulted in shared allocation of support between family, friends, the wider community and then health and social care. The allocation of paid support hours is the last action in a personalised approach and as demonstrated in the cases tested, was oftentimes less than would have been anticipated.

1.2 Recommendations

There is opportunity and momentum to continue, enhance and spread this work more widely at each local level. Uniquely, there are now eight sites around the country with key personnel situated within homecare services that have experience in developing and delivering personalised supports and programme reform. There is great potential therefore, to harness this knowledge and momentum to achieve and sustain improved outcomes across services and cross-pollenate across regions. There is a high risk of losing that potential if focussed engagement with the sites ends.

The staff working groups suggest the next appropriate stage is incremental implementation in practice. While application to the wider CHO area is considered the ideal, a phased change process is considered most appropriate. The following section details the key recommendations to supporting such a phased change approach.

Establish National Protocols to Facilitate Transition to a Personalised Support Model

National level support and input is required to facilitate application of personalised supports within home care delivery. The following aspects have been surfaced as consideration points to be addressed within any programme or understanding of engagement at national level prior to implementation at local level.

- **Commitment to the roll out of personalised approaches** to home care for people with dementia or more broadly for home care generally.

- Development of a **steering group at national level** comprising local representation to develop national programme for implementation.

- Commitment to supporting such roll out at local level **addressing resource implications** from a human and financial perspective.

- The remit of **home care transitions to a whole person approach incorporating psychosocial needs** as well as personal/ physical care need.

- **Equal weight is given to psychosocial needs as well as the physical/personal needs** a person may have to support a more equitable allocation of support within a home care environment where demand currently outweighs supply.

- **Dementia skills** are incorporated as a prerequisite for home care delivery within future home care tenders.

- **Insurance considerations** are revisited with clarity provided on delivering out of home support (HSE home help & private providers).

- **Equal weighting of a) hospital discharges and b) community support** as a preventative measure for hospital admission considered within a whole system approach.

- **Collapse thresholds** for entry to 'types' of home care to facilitate needs based individualised assessments that do not pre-empt or determine needs.

- **Home care budgets are managed locally.**

- **Financial Resources** - Agreement on allocation of budget for home care that is personalised is required. Suggested options include:

  a. Utilise the full existing budget to support a personalised approach to care for all home care recipients.

  b. Ring fence an amount of the existing home care budget for specific groupings such as people with dementia to deliver a personalised approach to this cohort only.

  c. Provide additional funding to address the current supply versus demand challenges but incorporate a personalised approach to care delivery to home care.

- **Human Resource** - Commitment to resource and support the development of local implementation groups in each area with dedicated time and specific resources is required.

  a. Dedicated **clinical nurse specialist role to promote and lead** on the development of personalised supports.

  b. Local **implementation group** to support the planning, development and implementation of a personalised approach to care.

  c. Allocation of **specific supporting resources** such as facilitation expertise, administrative support.

  d. **Signposting as good practice approaches** to existing or additional resources such as: primary care teams, integrated care teams or review teams to support case complexity assessment and implementation.

- **Facilitate cross learning opportunities** across all areas involved in wider roll out of personalised services.

Establish Structures to Facilitate Transition to a Personalised Support Model

A development plan from a national perspective on the direction of home care services as it pertains to personalised supports would be necessary for local level adoption and implementation. Inclusion of both national and local representatives in the development plan design phase at national level would be beneficial to ensure the 'design' can be implemented successfully at local level.

The following structures are necessary to support a transition to personalised supports:

- ⮑ Rollout of this wider programme requires an overarching **framework of implementation** to be developed at national level with key stakeholder input that will comprise key action points towards implementing a standardisation of approach for all sites, whilst incorporating flexibility to facilitate individual local contexts.

- ⮑ Develop a **communication plan** for all key stakeholders at national and local level.

- ⮑ An **intensive facilitation process** is required to guide the relevant sites in their application of the work to be undertaken.

- ⮑ A **programme team** of existing staff should be formed and equipped with time and resources to lead on the rollout for each area.

- ⮑ An individualised **implementation plan** needs to be developed by each area to support rollout locally.

- ⮑ A facility of **engagement with national management** to support centrality of approach based on a national development plan for implementation of a personalised approach to care

- ⮑ Opportunities for **shared learning and cross-fertilisation** across all relevant programme teams should be created.

Implement nine core actions to support transition

The following core actions are required components of any programme of work undertaken.

- ⮑ Deliver **personalised supports awareness training** to the staff base of nursing, home care coordination, and home care providers (HSE, Voluntary and Private).

- ⮑ **Deliver dementia skills training** to front line staff.

- ⮑ Explore and test opportunities for **complex case discussion** within multidisciplinary environment.

- ⮑ **Explore care coordination** functions to support complex dementia cases at local level.

- ⮑ **Agree home care budget** alignment to the work programme.

- ⮑ Explore opportunities for the development of a **care and support network** (incorporating family, wider social network, community supports and health and social care) in the community.

- ⮑ Explore perceived challenges relating to **out of home support provision or transport** provision.

➲ Enhance the home care **pathway and underlying processes and practice** to support implementation of a personalised support response.

➲ Maximise existing and pending **national initiatives that can be leveraged** through coordinated efforts, to achieve greatest impact (e.g. national home help training to support increased dementia skill).

Position the Programme of Work within Primary Care Network Levels

Situating the programme in the appropriate space in the social and health care service to support best possible outcomes requires consideration. Should a further rollout of this initiative be considered, designated sites should cover a geographical spread that encompasses several of the proposed primary care networks in each of the identified areas. Positioning the programme at network manager level would support this reach to several primary care networks. This is a suggested space; however, this is of course dependent on the systems readiness for change within that structure. As the following recommendations focus on the actions required to support such a transition, the key point with positioning is that they are strategically positioned within CHO areas at a level that can have a significant reach, such as, for example, at local area level within the current CHO structures.

Situating a proposed programme within these structures is appropriate for the following reasons:

➲ This will be the **future structure** for community care.

➲ Any implementation programme will need to be able to **align with and complement the operational structures** that will have been developed.

➲ The membership of any programme team will need to be **strategically positioned within that operational structure** to have influence and impact.

➲ Supporting an organisational shift for home care requires the ongoing commitment and **collaboration of national stakeholders and at local level**, (i) senior management of CHOs and heads of services, (ii) directors and senior managers of relevant disciplines and services, (iii) front line staff. The commitment and shared vision of all will be crucial in the adoption of a personalised approach to home care.

Proposed framework of implementation

A framework of implementation to inform rollout across all relevant sites creating a standardised implementation whilst remaining flexible to individual contexts is proposed. It is proposed that this framework is driven at national level, with clear leadership in rolling out the programme to each designated area that has been agreed by national management.

A facilitated engagement process has been advocated by some participants at local level to support the implementation team convened in each designated area to undertake this work.

The process of facilitation adopted would be intensive, solution-driven, and capacity-building focused. The key steps of the framework would include:

➲ Seek commitment and buy in to a transition of home care to personalised supports at local level. Engage with pertinent local level senior management. Identify and resource key leadership for the implementation at local level and to work collaboratively with external facilitation. Identify and recruit key stakeholders across acute and community sectors for each site to an implementation group that has reach across some intended primary care networks.

➲ Build capacity of among the implementation team formed in each area to undertake the change programme of transitioning to personalised supports.

➲ Co-create an implementation plan with each team that addresses the core actions required to support this transition.

➲ Create a forum to support cross-programme learning.

➲ Develop a template of implementation that will enable each CHO to independently apply the programme to the remaining primary care networks that have not been included in this second phase.

Effective Implementation Team Composition at local level.

Personnel involved across the home care pathway should be active participants in the actual rollout of the primary care network and the programme team developed to support organisational change so that all relevant aspects of process, policy and practice are appropriately addressed. Situating the programme team appropriately to provide maximum opportunity for reach to primary care teams within the primary care network is vital. Creating such an environment in an operational structure that is transitioning to a primary care network structure in a phased fashion requires a flexibility of approach. It is necessary that any such environment of change can be created within:

➲ a team that comprises membership that will have reach across several primary care networks.

➲ a team that comprises members who will be retained and continue their functions when the primary care network is live.

- a team that can incorporate additional emerging representation within the primary care network structure.
- an implementation plan that is not dependent on aligning with the introduction of the primary care network but can be incorporated seamlessly into the primary care network structures when in place

Suggested Membership of the Programme Team Includes:

- network managers
- general manager of social care
- managers of older persons services
- primary care managers
- home care managers
- directors of Public Health Nursing or representatives
- allied health professional management or representatives
- hospital representation from social worker or discharge coordinator

This core membership, at an appropriate management level, is key to ensuring that the relevant critical points along the home care pathway are addressed to enable transition to a personalised support response. It is important to note that many of the representatives noted above have already engaged in the pilot programme in each of the eight sites and are therefore key assets already in place. There is now potential to achieve change and begin to scale up by incorporating additional colleagues across those disciplines and functions within a broader representation in each area.

Additional Membership

Outreach to additional representatives or invitation to membership on the programme team is important to enable the development of appropriate, helpful and useable resources. Suggested additional representation could include the following:

- Service users and family carer representatives.
- Representatives from voluntary and community groups that attend to social care need
- HSE training and education infrastructures
- HSE quality and professional development representatives
- Key bridging resources to the community generally

This additional representation would ensure that the key actions as identified above are realised through collaborative efforts. For example, within a dementia specific context the need to develop dementia-inclusive community services was one message that came to the fore in the work of the pilot programmes. Community representatives, such as a community development officer with access, to and knowledge of, multiple groups within the local community would be a key stakeholder to engage with. Their established reach to these groups could support an efficient and scaled approach to developing a dementia inclusive community.

While the examples shared relate predominantly to dementia and older person, services, the actual membership will be dependent on each group's local context and remit for roll out.

1.3   Summary

The pilot programme undertaken has provided a testing opportunity to each site in developing integrated services that are personalised within live environments. The groups have provided effective, quality-driven personalised supports for people with dementia. They have also identified pathway and system enhancement requirements that will support further application of this approach within home care delivery generally. A framework of implementation that supports area-led implementation of personalised supports as a response to home care needs creates an opportunity for standardisation of approach to home care that can also incorporate local contextual difference. The proposed next phase of engagement as described above focuses on incremental implementation into a live system beginning to scale this approach to care delivery across several primary care networks.

Incorporated within this proposed second phase programme is the creation of a template that will support independent application by each area to support a final scaling of approach across each CHO area in a further and final phase.

2.0 Background

This report describes a change process which was piloted in eight sites across Ireland to tailor homecare packages to suit the needs and preferences of individuals with dementia and to better integrate these supports across health and social care staff. The study is based on a rigorous qualitative analysis on staff perceptions of:

⮑ The current context within which supports are provided to people living with dementia and their families

⮑ The change process which they engaged in and the challenges and opportunities which they encountered as they sought to roll out a more personalised approach

⮑ The benefits and challenges of implementing this more personalised, integrated approach for people with dementia

⮑ The potential for widening the impact to homecare supports more generally and the steps which should take place to support this

⮑ The potential implications for costs and how improvements can take place within the current funding envelope

2.1 Context

Dementia is a neurodegenerative disease characterised by a progressive loss of cognitive and functional abilities and social skills, often impinging on quality of life and the individual's capacity for independent living. Historically, the healthcare system has been residential care centred and there has been a lack of investment in the services

required to support independent living for people with dementia in the community. Hospital discharge is prioritised within the home care budget with hospital prevention receiving less attention.

In 2014 the HSE Older Persons' Services began a process of strategic realignment of the existing model of home care services towards home care and community support services. A key driver of this strategy was the provision of €10m funding to address pressures on acute hospitals through the allocation of individualised IHCPs. This allowed the provision of a greater range and level of services to older people and their families (HSE, 2014). This IHCP initiative also aligned with the NDS).

Following the publication of the NDS at the end of 2014, the HSE and The Atlantic Philanthropies jointly developed and invested in a programme aimed at supporting the implementation of the strategy. The National Dementia Strategy Implementation Programme (NDSIP) has three priority action areas, one of which is the further development of integrated services for people with dementia – particularly home support. As part of the IHCP initiative under this action, the HSE prioritised the rollout of IHCPs for people with dementia in nine sites across Ireland over three years (2015-2017). A fund of €20.5m from Atlantic Philanthropies, the HSE and the Department of Health was made available to deliver dementia focused IHCPs over these three years.

An evaluation and support arrangement was built into the NDSIP. Under a Service agreement with the HSE, Genio's role was to:

1. Support the HSE in the development of a suite of indicators for IHCPs and related data collection tool and provide on-going data analysis and reporting of IHCPs, with a focus on IHCPs for people with dementia. Report 1, titled *Supporting Older People with Complex Needs at Home: Evaluation of the HSE Intensive Home Care Package Initiative - Context, Recipients and Costs* (Keogh et al 2018) which can be found here www.genio.ie/dementia-report1-ihcp

2. Design, manage and undertake an in-depth study of a sample of dementia focused IHCPs to evaluate their effectiveness and how well they are working. The conduct and findings of this in-depth study are the subject of this Report 2, titled *Supporting Older People with Complex Needs at Home: What Works for People with Dementia?* (Keogh et al 2018) which can be found here www.genio.ie/dementia-report2-ihcp

3. Support the HSE in the implementation of personalised dementia-IHCPs which is the content of this report 3 *Developing integrated, personalised supports for people with dementia: Recommendations based on learning from the implementation of a programme across eight pilot sites in Ireland* www.genio.ie/dementia-report3-personalised

A central factor of the DSIHCP's was their ability to be flexible and tailored to the assessed needs and preferences of the person with dementia and their family members, with the aim of personalising service delivery. While there had been good examples of personalised care demonstrated through the care packages active at that point, for some staff there were challenges shared, including how to deliver a personalised support response and what it could entail as a package of care and how best to integrate supports in the local service environment. There was a perceived challenge in engaging effectively across the hospital and community settings in supporting the person with dementia as they transitioned from the hospital setting to the community.

2.2   Objective

The pilot programme **'Developing integrated services that are personalised for people with Dementia'** emerged in response to the early learnings from the national initiative of delivering up to 500 from DSIHCPs. The pilot programme sought to address the following three objectives:

i. Outline the salient lessons from the implementation in sites where approaches to personalising homecare packages were piloted

ii. Evaluate the most effective change strategies from the pilot phase

iii. Recommend processes for the wider rollout of personalised supports to homecare for people with dementia

Genio, an organisation that specialises in supporting reform of social care and health services towards personalised supports, was commissioned to develop and deliver this pilot programme. The HSE selected eight

sites aligned to specific hospital catchment areas where multidisciplinary local staff teams could work together using specific packages to develop integrated services that were personalised for people with dementia. The sites selected were:

Local Health Office Area	Acute Hospital	Community Healthcare Organisation (CHO)
Dublin North	Beaumont Hospital	CHO area 9
Dublin North Central	Mater Hospital	CHO area 9
Dublin West	Tallaght Hospital	CHO area 7
Dublin South East	St. Vincent's Hospital	CHO area 6
Waterford	University Hospital Waterford	CHO area 5
Cork City	Cork University Hospital	CHO area 4
Limerick	Limerick University Hospital	CHO area 3
Galway	Galway University Hospital	CHO area 2

The initial framing of these supports was as 'dementia-specific intensive home care packages'. Therefore, the initial anticipated recipients prior to engagement at pilot site level were mainly individuals considered to be at an advanced-need stage. However, the programme at each pilot site ultimately incorporated people at varying stages of dementia and need reflecting the appropriateness of a personalised approach to care for people at all stages of dementia.

Although the focus of the programme was on people with dementia and their families, most of the lessons from this study have a high degree of relevance to the wider issues relating to integrating and personalising community-based homecare supports in resource-constrained environments.

The term "personalised" as applied to community supports in this report, is a broad term used to describe different ways to support people with dementia to maximise their abilities and enable them to remain living a full life. Such supports include the range of physical, personal and psychosocial needs that a person with dementia may have and gives equal weight to these support needs required by the person to have a full, meaningful life. A personalised approach to care is designed with the person with dementia and their primary carer.

3.0 Methodology

The model of intervention that Genio employed to undertake this pilot programme is based on evidence of 'what works' when introducing service changes to health care settings, specifically using the action research method of organisation development.

Many initiatives to improve patient care have been developed over the years, yet their adoption into systems has been difficult and is often incomplete. There are many reasons for this including individual or organisational barriers to change; or equally the way in which change is implemented can be ineffective (Grol et al, 2013).

Organisation development, as an approach to changing healthcare organisations, pays attention to process as well as content, recognising the importance of how change is implemented as well as what is changed (Coghlan & McAuliffe, 2003).

Action research (AR) is a method of organisation development that brings together behavioural science knowledge with existing organisational knowledge to solve real organisational challenges. It is concerned with supporting change in organisations, developing self-help competencies in staff and adding to scientific knowledge (Shani & Pasmore, 1985). Importantly this method of research is undertaken with people rather than about people, respecting their knowledge and capacity to understand the problem within their community and how it might be addressed (Brydon-Miller et al., 2003). It brings frontline staff, middle management and senior leadership into a process where they are supported to navigate the challenges and develop solutions on how best to personalise and improve services for people with dementia.

3.1   Data Collection

Stakeholders involved in home care delivery from hospital and community settings at the eight sites were invited to partake in a phased programme of work that incorporated:

➲ Individual in-depth meetings with Genio to identify current practice, and the existing landscape of care delivery. Each individual meeting lasted approximately one hour and comprised discussion on the following topics: DSIHCP, home care, communication, integrated working and community services. **Approximately 159 individual meetings were undertaken.**

➲ Membership of a working group forum in their area to develop and test integrated personalised supports for people with dementia. On average, the working groups met five times over several months. Membership included representation from both hospital and the community **including nursing, home-care, care coordination, allied health professionals, senior management, discharge coordination and emergency department, social work, integrated care team representation, psychology, psychiatry, SAT assessment, CNS Dementia Mental Health, POLL, Dementia Advisor.**

Data collection has occurred at all stages of the programme ranging from initial intelligence gathering at group and individual meetings and throughout each of the five working group meetings subsequently convened with each of the eight sites. Data collection occurred variously through note taking, tape recording and facilitator's reflective notes. Consent was sought from

each individual involved, and non-attribution of quotes guaranteed.

Feedback, updates and collaborative working were key aspects of this project and occurred in the following way invested key stakeholders outside of working groups. Communication between all parties involved in the pilot programme occurred in the following ways.

i. Interim feedback was shared by Genio with the National Dementia Office

ii. As required, engagement took place between Genio and National Specialists particularly when live testing cases for input re process and allocation of funding

iii. Interim updates were shared by Genio with senior contact person in each of the pilot sites

Communication mechanisms were enhanced throughout the duration of the pilot programme, particularly in relation to engagement with national specialists at their request.

3.2   Facilitative Process

The three components required to undertake this work are:

i. Intensive facilitation

ii. Personalised support ethos

iii. Local capacity

Intensive facilitation was provided by Genio with the support of two Dementia Programme Managers and a Capacity Building Coordinator who created, developed and delivered an approach to change that

sought to facilitate identification of a core issue by local staff and to work collaboratively with a representative group to:

- Articulate the challenge.

- Create a response to addressing that challenge.

- Test and refine the response.

- Share their learnings to inform a wider audience in each area.

A framework of implementation was developed to assist navigation of the above actions with each group creating a clear road map to achieving successful outcomes. Facilitators enabled the content, direction and application of the work of the programme in each area to be designed, tested and implemented by the working group members. This was a very individualised process with each group and was therefore open to change and adjustment pertinent to the local context and the emergent learnings that occurred as the programme progressed.

3.3   Meetings of the Working Groups

The working group meetings were used to define the current context, develop a personalised approach to care delivery and explore the process of implementation by 'real case' testing and home care pathway development. Key learnings were extracted from the processes undertaken, including the impact and recommendations for next steps. Separate reports are being written for each individual site.

3.4 Inclusion Criteria and Recruitment

The main criteria for inclusion in the full pilot programme was that personnel were involved at some level in the pathway of home care delivery. Recruitment was initially through a designated senior management contact in each area who had local knowledge of key stakeholders in both hospital and community settings. There was scope within the programme for these stakeholders to identify additional personnel for Genio to engage with. A key programme contact was identified by senior management for Genio to work alongside in gaining access to key personnel.

In the main, Genio invited all personnel engaged with at the individual meeting stage to become members of the working group. The exceptions to this were instances where there were multiple representatives of the same discipline. In those instances, senior management identified a single representative from the list to invite. Individuals were free to accept or decline the membership invitation as they wished.

Genio sent the invitation to be part of the working group to the relevant individuals. Much of all coordination of membership and meeting organisation was undertaken by the Genio team with support at local level regarding meeting space and catering needs. In total, data from nine working group meetings across eight sites were analysed to inform this report.

3.5 Data Analysis

Thematic analysis was used to analyse the tape-recorded data. Thematic analysis is described as perhaps the most widely used method for identifying, analysing, and reporting themes that emerge from the data (Braun and Clarke, 2006).

Analysis began by reading and re-reading each transcript. During the re-reading a manual process of generating the initial codes was conducted. The transcripts were then uploaded to qualitative analysis software NVivo and the process of generating higher level codes began. This was a highly iterative process of refining the themes. This rigorous approach was enhanced through a collaborative coding process in which two members of the research team coded the transcript separately and then reviewed where their coding was similar and divergent. It was important to go beyond simply describing the findings to present a clear and compelling argument in response to the research aim. All the findings are presented by themes, with relevant quotations from the participants used as evidence in each theme.

3.6 Limitations

As outlined above, this report is based primarily on staff perceptions and interpretations of more personalised approaches in home care. As such, it should be seen primarily as an account of the journey of these staff and their views on their own roles, their capacity to integrate their work, their changing relationships with service users and families and their experiences of attempting to use limited resources more cost effectively in personalised ways. The process of engagement that was undertaken in each pilot site is described within Section 4.

4.0 Underpinning Facilitators Required to Support a Change Programme in Each Pilot Site

The following section describes the primary facilitators that were developed to enable a successful undertaking of the change programme in each area.

4.1 Commitment and Buy-in from Key Stakeholders

Staff's receptivity was the most important initial facilitator to supporting the change programme in each site. Representatives from hospital and the community involved in home care delivery were active participants informing all stages of the change programme and contributing to the direction and content of the work as new learnings emerged.

Management at a National Level

Senior management at a national level demonstrated:

- Commitment and support of this pilot programme with openness to adjust and adapt processes as new learnings emerged. The inclusion of allocated funding to support live testing of a personalised approach is one such example.

- Ongoing communication mechanisms between the programme team and the National Dementia Office throughout the process. This also informed live environments such as the National Dementia Specific Intensive Home Care Package initiatives. One such example is the inclusion of referrals for DSIHCP from community and not only the hospital setting as had initially been the case based on early feedback shared from the initial meeting stages at individual level in the pilot sites.

Senior Management at Local Level

Commitment to this programme was evident through senior management's contributions to the overall programme of work.

- They shared their own time and expertise with the Genio team.

- They identified and coordinated access to staff and supported the allocation of time for staff to engage in the overall programme of work.

- Access to space and facilities to undertake the programme of work within the 'workplace' of the working group members was also facilitated.

Frontline Staff

A wide representation of frontline staff met with the Genio team in the initial stages of the programme and shared their perspectives on the existing landscape of care delivery. Staff who collaborated with working group members, particularly in the implementation phase of case testing, embraced the vision of the programme and undertook a personalised approach to care delivery specific to their remit.

Working Group Members

Participants of each working group were active and contributing members during the pilot programme. Throughout, they demonstrated their commitment to the process by:

- Sharing their expertise through the design, implementation, and review phases of the programme as they worked to test and apply a personalised approach within their working environments.

- Being available for additional individual or small group meetings held outside of the structured working group meetings to progress the work, particularly during the live testing phases.

Hospital stakeholders

Emergency Department
ED Assistant Specialist

Discharge coordination
Hospital Discharge Coordinator
Hospital Integrated Discharge Manager

Allied Health Professionals
Medical Social Worker
Occupational Therapist

Allied Health Professionals
Occupational Therapist
Occupational Therapist - Psychiatry of Later Life
Social Worker - Psychiatry of Later Life

Home Care Working Group Membership
Wide range of disciplines represented

Senior Management
Manager for older persons' services

Care Coordination
Community Care Coordinator
Dementia Care Coordinator

Nursing
Public Health Nurse
Ass. Director of Public Health Nursing
Registered Community Nurse
Community Mental Health Nurse
Clinical Nurse Manager
Clinical Nurse Specialist

Home Care
Home Care Manager
Home Help Coordinator
Home Care Coordinator
Private Home Care Providers

Community stakeholders

4.2   A Framework of Implementation with Intensive Facilitation

A six-phase framework of implementation was developed to support a change programme in each of the sites. The process was delivered by the Genio team to support each site to navigate this framework at a pace and approach pertinent to their local context. This phased framework of implementation supported each area to:

Phase 1	Identify and collate information about the existing landscape to inform context
Phase 2	Develop a forum in each site to explore teh findings from the inital intelligence gathering.
Phase 3	Develop a personalised approach to care delivery, relevant to each local context.
Phase 4	Test the concept within live practice.
Phase 5	Capture and refine learnings and inputs from this testing phase.
Phase 6	Share outpus and recommendations with senior local and national management in each area.

4.3   Integrated and Collaborative Working Group Forums

The overall purpose of the pilot programme was to develop integrated services that are personalised. Collaboration was a focal point of the work and this began with the development of the working groups in each area. The working groups themselves were welcomed by most staff as opportunities to work collaboratively in testing an approach to care. The following were developed as key components of these groups:

- ➲ Local **expertise from hospital and community** across a range of disciplines and services were brought together to address perceived local challenges to home care.

- ➲ **Hospital and community sectors were connected**, becoming more aware of each other's experiences, perspectives, and the constraints they work within.

- ➲ A 'space' was provided where previously fragmented and siloed conversations could happen more cohesively.

- ➲ A relevant **personalised working approach** pertinent to the local context of home care was co-defined by practitioners working in the domain of homecare.

- ➲ A **shared language and narrative** was developed to describe personalised supports and infuse the process with a standardised approach to care delivery for the test cases.

- ➲ An ongoing process of **shared learning space** was facilitated within the group, resulting in new resources being developed and new learnings emerging.

- **Disciplines and functions not usually involved in home care application** processes were included and were active participants. e.g. Psychiatry of old age representatives and occupational therapy.

- The group dynamic provided a space for **open and frank** discussion among participants to achieve consensus of approach and greater understanding of different perspectives and experiences.

- A shared vision of **placing the person with dementia at the centre** of service delivery was developed.

- A **'collaborative effort'** of input by multiple disciplines and functions provided good outcomes.

- Opportunity for **peer reflection** as a supportive tool was valued, particularly for those who felt they were working 'alone' in practice.

4.4 Live Concept Testing of Personalised Working through Real Case Implementation

A critical facilitator to achieving positive results from the pilot programme was that personalised supports that were developed in each group could be live-tested within services. Each group chose several real cases to test their approach to personalised supports.

For the purposes of the live testing element of the pilot programme, the HSE allocated each working group a sum of €3,000 (€1,500 X 2) per working group per week. Initially

this level of funding was to equate to 2 high level IHCP. These funds were designed to facilitate each group in testing their theory to personalised working in real practice. Each working group temporarily reduced into sub-groups to consider and bring forward real cases of people with dementia requiring support. Through a process of presentation, discussion, clarification and agreement by the wider working group, the sub-groups proceeded to live-test an approach to care delivery.

The original vision was for each group to test two dementia-specific intensive home care packages. However, in all sites, personalised supports were adopted as an approach to care. As the ethos of a personalised approach to care is that a person with dementia will have individual needs that cannot be pre-determined and will not 'fit' into a 'band' of services, no group limited the case type that would be accepted for testing, other than that the person had dementia.

The cases tested covered all stages of dementia from mild, to moderate and advanced stages. This broadened range of case types accepted for consideration by the groups has demonstrated the relevance of a personalised approach to care across the continuum of dementia.

The funding allocated to each working group was therefore used to provide a range of supports to a larger number of individuals in each site than originally anticipated. The supports that have been implemented will remain with those individuals until they enter long-term care or come to end-of-life. A total

of 59 cases were considered for live testing across the eight working groups. The content of this report is informed by these cases.

The benefits of facilitating a live-testing environment for application of the espoused theory of the group are as follows:

- ➲ Testing within a live system provided the opportunity to **test a concept in real time and within real local contexts.**

- ➲ It provided an opportunity to e**xplore the underlying processes and structures** that exist and how they might be impacted or need adjustment to incorporate a personalised approach.

- ➲ Live case testing ensured that the **enablers and challenges** to implementing a personalised approach could be identified.

- ➲ The actuality of real-time testing **introduced a broader staff base** than that of the working group to a personalised approach to care delivery with very positive outcomes.

- ➲ Live case-testing ensured the pilot programme was not a discussion group with minimal impact but rather an **implementation group** testing change in practice in a live environment.

All the above structures and facilitators were necessary components to substantiate the process in a positive and supportive environment. Utilising the collective expertise of key personnel within home care to achieve a relevant response to local challenges and to test the theory in real time set the environment for building capacity and contributing to new learnings for service delivery.

5.0 Pilot Scoping Process

As part of the pilot programme an initial scoping exercise took place across the eight sites to establish the landscape of service provision that existed at the inception of this programme of work in each pilot site area. This collection of the main themes relating to the existing landscape provided context for the groups to begin their programme of work. Informed by the emerging themes, the working group created the components of a desired model for service delivery that was personalised. Using this model and considering the pathway of DSIHCP delivery the group tested it within a live environment.

5.1   Existing Landscape of Service Provision

Initial intelligence gathering was undertaken at each site by meeting with key stakeholder groups and individual staff members across hospital and community settings to gain their insight and experiences of home care package delivery and DSIHCPs.

5.1.1 Current Home Care Model

Participants described the homecare system generally at the outset of the intervention as overstretched for all those in need of home care support. They referenced increasing demand from an increasingly aging population and a lack of funding and services to address the needs of people with dementia. As one participant describes;

"You're trying to rob Peter to pay Paul with a never-ending bundle of applications coming across your desk every single day." (WG2 M#5)

Home care delivery was described as:

- Needs-based but budget-driven
- Personal and physical-care focussed
- 'Time to task' in approach
- Limited in flexibility and responsiveness when delivering supports
- Oftentimes is crisis driven

Participants highlighted the disconnect that exists between their perception of need on the ground and the reality of the response that could be delivered. Participants reflected on how they were "enshrined" in a personal care needs focus so that when a non-physical need presented their thoughts were:

"There is nothing I can do about that". (WG4 M#4).

"….it's emphasised that you won't get a home care package unless they need personal care. So, you're going into the house saying do they need personal care?" "And it's so drilled in."

Participants also considered the challenges faced by people with dementia *under the age of 65* within the current home care model. Although they have distinctive needs due to their age and stage of life, the support available was only for personal care.

The current environment of 'home care packages' was also described as consisting of waiting lists with prioritisation processes that do not sufficiently reflect the multifaceted needs of the person with dementia. Because home care is personal/physical care focused

only, the wider range of needs that a person with dementia has, such as psychosocial needs, are not equally weighted. Within systems whereby prioritisation tools are used, people with dementia whose needs are more in the psychosocial domain tended to be in the priority two or three brackets rather than the priority one bracket that was most likely to receive support. This meant significant periods of waiting for supports and a perception by staff that the person would not receive supports until they progressed to a point of physical or personal need leaving their psychosocial needs never addressed.

Participants shared the constraints of the system they work within, agreeing that as a result, the focus for both family and staff can be accessing as many hours as possible for the person. Others shared instances where it was perceived that excess home care hours were being delivered to some clients. This was particularly shared in cases where the person received a home care package to facilitate discharge from hospital. There was recognition that the persons needs may change over time and the support could be reduced but that it was difficult for staff to take away support hours. Sites referenced the benefits of separate review teams to undertake this work.

Staff reflected on the lack of trust in the system that existed among some family and staff because of the constraints in home care delivery. They reflected a reluctance to reduce care that was known to be more than the persons current needs, as there was no certainty that the level of care would be increased if the persons needs increased in the future.

Participants also perceived that inappropriate hospital admission to access care could provide a better outcome than if an application was made from the community for home care. Examples were shared where the narrative within the hospital setting was that people had been told to come into the hospital to access the DSIHCP. From the community perspective, the initial limit of the national DSIHCP accepting referrals only from the hospital setting, appeared to support this perception. While the DSIHCP subsequently incorporated referrals from the community as well as the hospital, the above perception was an emerging theme from those we spoke with about the existing landscape at the time of the project start. Other examples shared Perceptions of inequity in the system as different geographic areas offered different services, leading to clients questioning why one area could receive a support type and another area could not. Participants reflected on how this perceived inequity made interactions with families challenging at times. They shared a felt responsibility in managing the expectations of families, limited by the scope of the supports they could provide.

Additionally, participants from varying disciplines, grades and service areas, identified the need to be knowledgeable about dementia to provide appropriate and informed support. They also identified the challenges in supporting the multiple needs of people with dementia. They considered how during the pilot programme time frame there was no HSE requirement for dementia-skilled staff to deliver supports for people with dementia. Participants perceived this as challenging for all involved: people with dementia, families, home care staff, providers and health services.

The additional challenges of delivering supports in an environment of staff shortages and attrition and working with multiple public and private providers were also highlighted. Groups share many instances where home care has been approved but there are no staff to deliver that care. Participants also share the sense of a lack of ability to co-ordinate care to the needs of the person because of the limitations of the care provider resulting in a support plan whose timing of delivery is suited to the provider rather than the person. Others share how a large package of care is very challenging to fill as it will entail a high number of carers going into the one home which is to the detriment of the person with dementia and their comfort. Additionally, groups reflect how these large packages are more difficult to fill and may end up going "round and round" as providers struggle to meet the need. As one group shared, a 42-hour package equates to 10 or 12 carers and in a climate of staff shortages, coordinating that for one care package is difficult.

From a service delivery perspective, staff shortages mean that staff have also shared the risk of removing support that is not for personal/physical care from a person with dementia to meet the needs of another who has personal/physical care needs. Additionally, as a staff member moves on from a care role, one group shared how this couldn't be replaced for the client in receipt of care.

The large range of providers that are being engaged with is also challenging for the HSE. Many have reflected the large number of

providers that are approved but who have not engaged in service delivery at all and yet remain as approved providers. Additionally, the lack of reach by providers into rural black spot areas is particularly challenging.

5.1.2 Dementia-Specific Home Care Packages – Operational Experiences

Most participants recognised that there was a specific cohort of people at advanced stage of dementia who needed this level of support and the majority of those involved in DSIHCP cases shared very positive outcomes for the person with dementia and their family.

Some challenges were also shared, including uncertainty over the availability of care packages. This could impact on the ability of staff to engage confidently with families in need as well as create a risk of raising expectations that might not be realised.

Because demand for these packages outweighed availability, some sites decided to prioritise developing protocols, waiting lists and/or approval forums to support decision making on who would receive the package of care. Other sites adopted a more informal approach and responded as a case became available. Many participants were conflicted about their local processes to support robust decision-making about who should receive the support package.

Within the eight pilot programme areas being discussed in this report, many staff reported a felt sense of urgency to return applications for DSIHCP quickly once availability was

announced in their area. One example reflected a turnaround time of half a day, another example reflected notification of availability on a Thursday of a bank holiday weekend for return on the following Tuesday. Reflections on the perceived fast turnaround of applications centred on concerns about identifying the most appropriate client when working in such a constrained time frame to "source" the right client and how this was moving away from a person-centred response.

A sense of competition was also shared as some felt a fear that another case in the area might be accepted before theirs if their application was returned more promptly. There was also concern that if a case wasn't allocated promptly within their area that it could be reallocated to another area. It is important to note that these reflections were shared at the beginning of the pilot programmes in several pilot sites and does not reflect any subsequent changes made to process after that time or indeed does not reflect the experience of all pilot sites.

When discussing DSIHCP, a topic that was frequently raised was that of fairness and equity within a system that is currently perceived as highly resource-constrained. While people did not question the need for intensive support, they felt that supports were being allocated in an environment where need heavily outweighed the available resources. For some, this was considered an ethical issue in providing an intense service for the *"chosen few"* (WG1 I1). Concerns were also raised that the number

of hours for the DSIHCP were too high for some people, particularly those who were previously receiving low levels of support. It was believed that this sharp increase in hours (rather than an incremental approach) could negatively impact the person with dementia and their family. One example shared related to the allocation of 25 hours support for a person with dementia. While this was welcomed by the family, their request to reduce the number of hours to 15 was refused as this would take them out of the DSIHCP threshold of entry bracket.

For one site, creating an additional pathway for this group was perceived as being unhelpful as the principles of a person-centred approach should, it was felt, be uniform across the service of home care delivery. The intensity of supports provided as part of the DSIHCP pathway was felt to be challenging as it prioritised only intensive need, rather than incorporating support for all stages of dementia, which could result in delaying some premature progressions to intensive support needs.

Amongst the participants there were varying degrees of understanding, regarding the scope of the DSIHCPs, particularly amongst those who were not centrally involved in administering them. This was perhaps due to the limited number and uncertainty of availability of packages coming into an area which in turn limited the communication undertaken to not raise expectations that might not be met. However, staff noted their wish to have been more informed.

5.1.3 Communication

Information about the national initiative and its purpose had been communicated to senior management and staff involved in implementing these packages. Participants not directly involved in administering these packages were less aware of their existence. Some participants suggested that representation on the approval forums should be broader to include staff that know the person with dementia and can advocate for the case.

Additionally, an input and feedback mechanism between frontline staff involved in delivering new initiatives and the national group involved in designing the initiative was suggested to underpin a refined process.

5.1.4 Integration and Collaboration

Integrated and collaborative working among staff, disciplines and services to support good care delivery was valued among all participants, with good examples shared within local areas such as integrated care teams. These examples ranged from various forums or multidisciplinary groups that existed to complex case discussion that supported hospital discharge. Some examples included:

- ➲ the roles that provide a bridge between hospital and the community, such as public health liaison nurses or integrated discharge roles
- ➲ specialist services such as psychiatry of later life
- ➲ mental health teams
- ➲ community social workers
- ➲ dementia specific roles

It was noted that these processes worked particularly well in relation to complex cases. However, access to these services and disciplines differed across the engaged areas.

Participants also reflected on the constraints that existed in their services and therefore the delays and lack of input that could be problematic in addressing such cases. In some instances, the strength of the collaboration depended on the one-to-one relationship building that had taken place over a prolonged period. There were also examples shared of siloed approaches to care delivery and its impact on family members as well as staff in the duplication of work and the separateness of approach. The lack of integration present was viewed as being a contributing factor to misunderstandings about the calibre, efficiency and remit of other staff.

5.1.5 Community Services

Community services that are dementia-inclusive make a valuable contribution in encouraging people with dementia to live full lives. The services that might be considered are those that are specifically dementia-inclusive or older-person focused, as well as ordinary services in the wider community that may be dementia-inclusive. (e.g. shops, clubs, sports, choirs etc.) Most participants did not identify any ordinary or 'normalising' activities that a person with dementia could engage with in their locality.
In the main, people described Alzheimer's services, day care centres, Meals on Wheels and dementia-specific services. Local knowledge of the services available was key.

Waiting lists for some of these services and refusal of support for people with responsive behaviours were highlighted as being particularly challenging.

5.1.6 Personalised Supports

When discussing the current home care model and the DSIHCP model, people were asked to share their solutions to the challenges that they perceived in both. In many situations the solutions proffered were components of personalised supports.

As such the change programme which is the subject of this study should not be a new model introduced externally but rather a process of developing and expanding elements of existing best practice from within HSE services. Person centred approaches to care have been undertaken within HSE services, with progress impacted upon because of cutbacks and other issues over time. A personalised approach, which has a broader consideration than how support might be delivered but considers by whom it is best delivered and how normalising the approach to support can be was an expansion of the thinking of a person-centred approach to care.

Key components to be included within a personalised approach to care were shared:

- Personalised supports should be designed with the person with dementia and their family

- A needs-based assessment incorporating physical/personal and psychosocial needs for people with dementia is required.

- Home care supports should have greater flexibility and include overnight, weekend and block support-hour options that could be responsive to changing needs.

- Supports should be available in and out of the home.

- Maintenance of a support connection and inclusion in the community should be emphasised.

- Respite supports need to be mutually beneficial to both the person with dementia and their primary carer.

- Supports are provided by family, wider networks of friends and neighbours, the wider community, social and health care.

5.1.7 Summary

Generally, participants characterised the existing homecare system as one that was over-burdened and under-funded. It was perceived that the current system had an ingrained cultural focus which prioritised physical care over other needs that a person with dementia might require living as well and as "normal" a life as possible. Participants reflected on their awareness of an increasing need for services to support people with dementia with additional needs that resulted from their diagnosis such as in planning and organising, daily task completion and social participation. There was acknowledgement of the gap between this ideal and what could currently be delivered.

This gap was identified at the outset of the programme and attributed to a lack of funding resulting in a lack of capacity within services for people with dementia. Lengthy waiting lists for services were often highlighted as a reality for people with dementia and their families. The system was also perceived as fractured with agencies and

disciplines frequently working differently and disjointedly across different areas and regions. Participants understood the elements of what personalised supports should look like.

The collation of the above data relating to the existing provision landscape provided context for each working group as they considered solutions to the challenges identified for home care delivery in their area.

5.2 Testing a Personalised Approach to Local Care Delivery

A key enabler to the development of a personalised approach to care delivery was the allocation of dedicated time and resources to key individuals involved in home care across hospital and community settings. Representatives from both settings came together to work on a change programme that sought to design a personalised approach to care as a solution to the local challenges identified within each area. As part of this process, groups were able to:

⮑ consider their existing local context and the parameters they work within

⮑ agree their desired future state for service delivery in the area

⮑ identify what challenges might present in achieving that goal

⮑ identify solutions to how those challenges could be overcome

5.2.1. Designing Supports with the Person and their Family

As each group defined what designing supports with the person with dementia and their family should consist of, they included concepts such as:

⮑ listening to the client and family to determine what they need to support them

⮑ being transparent in the engagement, being clear about what could be achieved

⮑ going at the pace of the person with dementia and their family, recognising that they may need time to come to terms with the condition and to engage in this way

⮑ having a focus on maintaining the strengths of the person

⮑ adopting a 'designing with' approach as the norm for how care assessments are undertaken

The above aspirations for service delivery were contrasted with the current approaches to service delivery which were perceived as being:

⮑ a pre-prescribed "menu of services" that limit the type of support that can be provided

⮑ limited in the openness and collaborativeness that can be fostered with the person and family due to limited supports available

⮑ because of intensive work loads and staff shortages, time is therefore limited for staff, creating a focus on what can be given from the "menu of services" rather than what is needed and how that might best be delivered

⮑ having a deficit-focused approach to care exclusionary of the person and their family because assessment of need can occur between professionals using technical jargon and focussed on their own goals.

The groups advocated for the need for a different type of conversation to occur between all parties revolving around how home care for people with dementia is delivered.

Whilst challenges such as perceived complex family dynamics or 'demanding' families were discussed, many participants recognised families as key partners in supporting a person with dementia and maintained they had significant contributions to make in how best to support the person.

Most participants reflected the need to move away from the "medical" person telling a person with dementia what to do: *"This is what we've got, take it or leave it".* (WG2 M#5). Instead, there should be a move towards a different engagement, with questions such as 'What are your most pressing needs?' or 'How might we help?' underpinning that communication. Participants shared how all too often 'the meeting' to determine need and allocate support is among professionals only without the person with dementia or their family present.

The best perceived way to identify the actual needs of the person with dementia and their family was to design supports with them. Creating open and collaborative discussion, with contributions from the person with dementia as well as the primary carer and the practitioner was considered vital in supporting a move away from packages of support that are prescriptive, unsuitable to the actual needs of the person with dementia or are delivered at too high a level for the needs presented.

5.2.2 Ability-Focused Supports

Participants expressed that people with dementia can be prematurely disabled and disconnected by the traditional deficit-focused approach to home care. There was a desire for a paradigm shift to move from the traditional approach of deficit focus that considers only physical need to an "ability-focused" support system that incorporates both physical care and maintenance of abilities. As groups defined what ability-focused supports should consist of, the following components were shared:

- Supports should be ability-focused rather than disability-focused.
- Emphasis should be on maintenance of ability including both physical, cognitive, and psychosocial capability.
- The person with dementia should be empowered to continue doing things themselves where possible.
- There should be purpose and goal-setting in any care plan development.
- There should be access to community services and resources as part of any care plan.
- Family carers contributions should be valued as they have personal knowledge of the person with dementia and have a role in creating a response to care needs.

Groups shared how this differed to the current model by listing the following aspects:

- Supports are currently deficit-focused, with carers assigned to support deficit.
- There is a focus on personal care only.

➲ Risk-minimisation is to the fore of care planning.

➲ Supports can potentially disable existing family support by being too intense too soon.

➲ Supports tend to be inflexible in how they are delivered.

➲ There is an in-home focus for place of care delivery.

➲ Supports are provided to complete tasks in short bursts of time that can inadvertently disable the person by being too rushed

➲ Care is delivered based on doing 'for' rather than 'with' the person.

➲ No value is given to a broader consideration of appropriate responses to meet support needs outside of the existing pre-prescribed types of services.

➲ Social care is regarded as the lowest level of priority.

All groups reflected that assessments carried out in the current model of home care are deficit-focused and *"point out what you are doing wrong but we very rarely point out what someone does well"*. (WG4 M#4)

In contrast, ability-focused supports as defined by the groups would focus on enabling the person with dementia to be as able as possible at any given point in their journey with dementia. Personalised support care plans would also have a clear objective and purpose for the support provided with a move away from passive deficit-focused supports to active ability-focused supports.

5.2.3 Care and Support Network

The notion of exploring the care and support network was felt to be the most challenging to engage with for the working groups in the initial design phase of the programme. While all groups were very clear about the importance of family involvement and health and social care involvement, there was less awareness about the potential of the social network of friends and neighbours and the wider community to become supporting partners in assisting the person with dementia to live a full life as normally as possible.

Participants were asked to consider what groups, organisations or services in the wider community could be supported to be dementia inclusive and supportive of people with dementia. In the main, the wider community that is the ordinary supports and services that anyone may engage with, were more difficult for staff to consider as supporting partners in a personalised support plan. This is perhaps due to the lack of a developed infrastructure that is dementia inclusive in the wider community. Groups were clearly able to identify the older person services and dementia specific services that existed whilst also highlighting the constraints that exist within these services. They highlighted the variance of availability across geographical areas and particularly in rural areas and raised the concern of how 'personalised' these services are in how they deliver individualised services that respond to need.

The purpose of this exercise was to explore who the broader range of stakeholders outside of the HSE might be who could be engaged with to further maximise the potential for a personalised support response that includes community connection.

5.3 Enabling a Personalised Approach to Care

As previously described, a core component of the change programme in each area was to live-test the approach to care that had been designed. Several key enablers to delivering a personalised approach to care were brought to the fore by each working group as they reflected on the work they had undertaken in live-test cases.

5.3.1 Utilising Supporting Assessment Tools to Enable a Personalised Assessment of Need

A sample personalised assessment form was shared with each working group to assist them in undertaking a personalised assessment. This resource was a facilitative aid as each sub group sought to test a personalised approach to care for a person with dementia for the first time. It was intended that this form would be completed with a CSAR form ensuring that both the physical/personal needs and the psychosocial needs were captured (See Appendix 2).

Most participants reflected that the assessment process and supporting documentation used for testing personalised supports was very helpful in supporting participants to gain greater insight to the needs of people with dementia.

The personalised assessment form combined with the CSAR supported staff to consider:

- Actual need comprising both physical and social consideration.

- Who might be the supporting partners to meet that expressed need.

- The creation of a support plan inclusive of all supporting partners' input.

Groups shared how this approach to assessment provided a more 'honest' reflection of actual need, which oftentimes resulted in fewer support hours being requested than would have initially been anticipated.

The following quotes exemplify how the assessment process prompted different thinking about the way supports could be met and drew on the resources that currently exist around the person and within their community.

"No, I feel that utilising that model they (staff) have really kind of focussed on utilising the services that were available to us with [project in the area with services] and by the time we got the family involved, who could take them to these services, we just didn't require the volume of hours we had requested. So, it worked out at four hours. It did highlight just, you know... ask." (WG2 M#5)

and

"There were two of the nurses who were involved in my case that I used and the nurses in fairness just asking them, 'How did they feel about using this?' but they learned so much because it was really bringing all your community services into play, not just home care, home care." (WG2 M#5)

Many groups have suggested using this resource, or an enhanced version, to support current practice, reflecting that it would support a more holistic and appropriate response to home care. This form is not a replacement for a CSAR or a SAT assessment form, but rather an accompaniment to these forms to address the psychosocial need identification and to assist with completion of a purposeful care plan.

It was also felt that the Barthel Index, a functional assessment tool, included with the CSARs that assesses a person's ability to complete basic activities of daily living does not reflect the needs of people with dementia with regard to ability to complete more complex tasks such as managing finances, organising and planning, housekeeping, shopping, meal preparation, managing medications and social functioning. As such it was felt, that home care packages informed by these assessments focus mainly on personal/physical care needs and heavily disadvantage people with dementia whose main deficits might lie in these other domains.

There was discussion as to whether the SAT assessment is sensitive enough to capture the relevant information, with opinion divided.

There was discussion as to whether the SAT assessment is sensitive enough to capture the relevant information, with participants acknowledging that while there is a narrative box with each section this does not guarantee that all the relevant information will be collated. However, the importance of supplying an accompanying narrative was acknowledged when it came to approving home care packages as reflected in the following quote.

"Well it's when you put the two together that's when you get the panoramic view, it's the panoramic view that you want and yet you don't want one without the…… other you actually need them both. And the SAT is better than the CSAR for these cases." (WG2 M#5)

Resource implications

Participants valued the process of the assessment used, sharing the belief that its more robust assessment and needs identification provided better outcomes and could contribute to time and cost efficiencies for services.

Some participants shared that a significant amount of time in practice was currently being spent seeking clarification of information at application stage or adjusting how hours were being delivered for individual cases at implementation stage. Currently, addressing these issues requires additional communication between staff as well as onwards to the family, which impacts efficiency across the homecare pathway. Groups felt that a personalised assessment as an approach did address these challenges for the cases tested as it captured all the required information in the first instance. The co-design element of the assessment also ensured that there was consensus between the person with dementia and their family and the practitioner about how and when the care would be delivered prior to the application going forward for consideration.

Some participants shared their feeling that the assessment process took more time than

would be taken using the tools of current home care assessment. Groups felt that this additional time and the process of assessment is *"necessary and you are doing a lot of the work up front" (WG2 M#5)*. This view was also shared by another group as they reflect *"it's trying to get into people's heads yes it's about resources, yes it's about time but if people actually looked at it in a more effective way it would take less time". (WG6 M#5)*

Discussions about additional time included exploration about a standardised assessment tool (SAT) and its required additional time for completion. Additional time was recognised as necessary to assess the person's needs appropriately. While the SAT assessment tool was a beneficial tool, for some it was too early in their experience of using the SAT within their practice to share if it would meet the full needs of the person with dementia from a personalised perspective. For others, it was suggested that a supporting narrative would need to be added to the SAT to fully share the range of needs that the person with dementia had and how they might be met. The personalised assessment form or a variation of it was suggested as an appropriate supporting narrative.

The assessment process used was also considered helpful for complex cases. However, when discussing case complexity, many participants shared a view that there was currently a need for a clinical nurse specialist to coordinate and support these cases as it was not currently feasible for nursing staff to deal with them because of the time involved and expertise required. As groups engaged in complex cases, some spoke of the need to have a shared and

multidisciplinary approach to case holding. Fear of being isolated in holding such cases particularly came to the fore in one site. However, all reference the need for expertise, dedicated time, and case holding until the case normalises as requirements to support complex cases. Complexity was evidenced in cases tested such as hospital discharges with rapidly progressing needs where broader support around the person advocated for long term care. The complexity of co-ordination, responsiveness, specialist input all came to the fore as challenges.

One group offered an opinion that complex cases should be assessed by a dementia-specific multidisciplinary team. While dementia specific multidisciplinary teams did not exist in any of the pilot sites at the time of the programme, primary care teams or integrated care teams were proffered in some instances as appropriate spaces for this engagement. In most sites where, integrated teams were up and running, there was a natural alignment to incorporating these cases within these domains with one site identifying a change in process that would incorporate DSIHCP assessment to be undertaken by the integrated care team.

In further discussions about the functions of such roles; case discussion, coordination of care and promotion of a personalised approach were deemed the critical functions to be fulfilled. Focusing on the functions rather than the 'role' allowed groups to consider whether these functions could be addressed locally within existing resources or if they needed to create the 'role' that would comprise these functions.

This assessment approach was also considered a helpful tool in reviewing existing home care packages. One group reflected that a personalised assessment/review could result in further cost efficiencies as actual need would be identified. While the group recognised that there may be staffing implications to carry out the reviews they reflected that they *"know that there'd be possibly a savings because we'd be taking back some of the hours."* (WG1 M#5)

The benefits of a different type of assessment supported a holistic needs assessment with possible time and cost efficiencies. It also provided a vital resource to support the application of a personalised approach to care at the front line because the data collected at assessment could be transferred through the pathway to implementation.

5.3.2 Including Supporting Partners in Care Assessment and Planning

Staff reflected how this aspect of the assessment process was key for them in identifying the full picture of support required around the person with dementia. It also provided the potential for further input by supporting partners.

Person with dementia

What are the wishes and preferences of the person in terms of supports?

What is the family able to do? Want to do? Do well? *That the person with dementia will find acceptable*

Who is available from extended family, friends and neighbours and what can they do?

What services, voluntary and community, are available to meet need?

Family

Wider Social Network

Community Supports

Social Care

Health Services

What existing groups and organisations could be supported to be dementia friendly and develop a supporting role?

What disciplines need to be involved to support the person's needs need?

The inclusion of natural supporting partners gave a concrete contribution to the personalised support plans developed for cases of people with dementia that were tested in each group.

The piece below reflects a participant's adoption of this approach as they considered all potential supporting partners and how they might be able to support the person with dementia.

"I think it was this notion of connection piece in maintaining the abilities piece again, trying to determine if there were elements, you know the exercise programme as well as those elements just to try and illicit more information to see was there opportunities there to maintain some connections. Obviously, the family have reconnected so it's about maintaining that as well, seeing how healthy that is, how close relationships are and trying to maintain that if they are" (WG3 M #3)

This process also illustrated for the groups the further potential that exists to create a more 'normalising' approach to support for people with dementia when the natural supporting partners of the person are valued

Family

In most test cases, families were providing significant amounts of support for their relative. Opportunities for additional family members to re-engage with the person with dementia and support reconnection to activities of interest did also occur. One such case example is shared below by a participant

providing an update to the working group on how the case is progressing.

"She's got a better quality of life because of all the intensity of hours (13 hours paid support) going in, because her son moved back in home to take over her care and she said she's never seen anyone like him.

But he couldn't do what he's doing without the support of the hours, and he has attended the [support service] and has implemented all of his learning with his mother, and is doing puzzles and anything else that he got education on, and has passed that around his siblings and has got everybody involved and trying to get his siblings a bit more on board so they have the same kind of understanding that he does.

He has learned about all of the services and linked in with Alzheimer's and apparently is delivering amazing care because he has the support of the intensive package". (WG2 M#5)

In some instances, family were not actively involved or living locally so engagement could only happen to a certain level. This narrowed the supporting options available for these cases.

Some instances reflected the challenges families continue to face with prevailing stigma. Support options such as family training and peer support were highlighted as very valuable resources for families to connect with to support them in their caring role.

Wider social network

The wider social network of friends, neighbours and colleagues were also active in supporting people with dementia among the cases tested by the working groups in this programme.

Some people were already connected with the person with dementia and their family. Any further opportunities for connections were made by the primary carer. This was felt to be more appropriate than a more formal engagement by staff. The role of the practitioner was to facilitate consideration of appropriate supporting partners for the individual.

For some test cases, family members or neighbours had been actively supporting the person with dementia for some time before the programme's intervention but were becoming uncomfortable about continuing because of the progression of the person's dementia or the perceived responsibility of caring for that person. With the input of personalised supports, there were opportunities for some of these supports to continue as individuals no longer felt they were carrying the burden of support alone. However, groups shared that in examples when this support came too late these partners may have already stepped away.

Because of this stepping away, the inputs from these categories of the care and support network of the person category was limited. In other instances, they didn't exist as the person with dementia had quite recently returned to live in Ireland from abroad or had moved from a different county. For this cohort, health and social care supports

become the main supporting partners because family input was limited or non-existent, the wider social network of friends and neighbours was limited, and the wider community may not have been engaged with previously. An added dimension for this group is the normal tasks that a family might support such as house clearing or sorting the recycling bins for example and how that becomes part of the persons support plan.

Wider Community

The wider community also has a key role in helping the person with dementia to remain connected and active. As shared by one participant, there is a lack of impetus more generally in creating normalising environments that support inclusion for people with dementia. This participant's opinion was that further work had yet to be done by the broader community as

> *"we're not trying to integrate them. We are in very small ways, we'll bring them off but we're not making them comfortable to make them go in the door of their local swimming pool or the local shop." (WG2 M#6)*

All groups actively sought out opportunities to include the wider community in the life of the person with dementia where appropriate. In most cases tested there were no instances where a community group, club or service independently supported engagement from the person with dementia. In most cases that connected the person with dementia to the community, paid supports were provided to be that connector. The only exception to this was one site that had developed community services and the family member brought the person with dementia to and from these services.

The groups learned that while the National Understand Together Campaign was a positive start in building awareness about dementia, there needed to be further investment to develop actively-supporting and inclusive communities. Some welcomed the development of the national community activation programme and some also saw potential in working with key stakeholder groups locally to develop an inclusive community. The potential for this engagement was more apparent for all participants having live tested cases in a personalised way.

Social Supports

Social supports that were dementia specific or older-person specific also had active roles in supporting people in the cases tested across the groups. For example, a person with younger onset dementia was connected to a dementia peer support group, a cognitive stimulation therapy class and a local lunch club as part of her overall personalised supports response. This was facilitated with the input of a paid support worker assisting her to navigate to and from these services. In the traditional model, these referrals could not have been actualised as the lady was unlikely to self-prompt or navigate to these services independently. As she lived alone with no family support, it is probable that she would not have been able to avail of these services, potentially resulting in a more rapid progression of her condition.

Type: Long term care avoidance	**Gender:** Female	**Dementia Diagnosis:** Alzheimer's, mild

Presenting Need: 60+year-old lady, mild Alzheimer's, living alone with no family in Ireland. Experiences anxiety, gets lost outdoors, forgetting to eat, house cold and becoming isolated. Independence is important for client, enabling support is crucial. Keeping active with life roles a focus. Already receives one hour a week home help.

Supports implemented: 12 hours support provided to facilitate independence, connection and assist with medication, nutrition and home heating prompts.

Total package: 12 hours a week allocated. Cost: €360.00

Purpose and objective: This lady was being discharged by Psychiatry of Later Life Team (POLL) with referrals to DREAM (dementia group), a cognitive stimulation therapy group and a local lunch club as well as prompting for meals, medication and heating of the house. In the traditional model this lady might have received supports re. prompting for meals, medication and heating of the house. She would not have received support to attend the activities identified by the POLL team. The purpose of these referrals was to support inclusion, connection and maintenance of ability. This lady could not self-motivate, prompt or navigate to these services and would not have been able to avail of said services in a traditional approach. The personalised approach took account of her specific needs, tailored her hours to incorporate both the prompting and social support needs, which it is anticipated, will enable her to maintain those abilities for longer. This cased has been supported by the POLL team and can continue to be so if necessary. It is suggested that this case is now best held by primary care team with access to POLL at times of change or complexity. While this case currently does not have a clinical need, their dementia need is clear, and it is felt therefore that this case best sits within primary care.

Several cases had already been or were supported to avail of day care services and these services were a valuable resource. Some participants also recognised that sometimes such services are not appropriate for the person and their stage of dementia.

For example, a pressure points for a gentleman and his wife, who were supported by one group, was that he was no longer comfortable in a day care environment. He had younger onset dementia, was very active and mobile, and became quite agitated in this space. This resulted in his wife having to leave work to collect him and bring him home. Providing an alternative support response that was individualised and appropriate to his stage of dementia supported this gentleman to continue with his routines and activities in his community for a period and supported his wife to continue working.

A further consideration for some working groups was the need to ensure that dementia-specific services or older-person services in the community were personalised in their approach. While these services were greatly valued by participants, some also shared their concerns about the "one size fits all" approach.

They questioned the appropriateness of full days for the person with dementia. They were concerned too about the perceived lack of input given to appropriately matching the person with dementia to a relevant activity of interest, with 'places' being allocated on availability of space rather than suitability of activities.

In addition, concerns were also raised about people with dementia being refused services because of preconceived ideas on behaviour. Even within these settings, stigma about dementia can prevail.

In all test cases, the supporting partners of the person with dementia were fully explored with opportunities for engagement considered. While personalised supports were provided in all cases, in some cases personalised supports were delivered with paid supports only. This was primarily due to undertaking a personalised approach at the later stages of a person's dementia when supporting partners such as friends, neighbours and the wider community had disconnected from the person. Within the broader community there was limited opportunity to engage with normal/ordinary 'services' or 'groups' that were dementia inclusive. Both scenarios reflect our current knowledge about the risk of premature disconnect from community of people with dementia and the need to de-stigmatise and develop a community infrastructure that is dementia inclusive. The Community Activation Group developed as part of the Understand Together Campaign is one such initiative set up to address this gap.

The groups' perspectives on the possibilities of these partners playing a supportive role changed over time. Having tested cases in this way, there was a shift to understanding the potential from more aware, informed and inclusive communities and services. Some groups also identified key stakeholders to engage with who would be vital connectors to a wide range of community groups, clubs and services in their own local areas.

5.3.3 Implementing Flexible and Responsive Personalised Supports

In testing personalised supports, working groups sought to adopt the principles of personalised supports at each stage of the process, from the assessment and approval

stages to the implementation of care and finally review of support needs. Supports that were ability-focused and attended to both physical/personal and psychosocial needs were considered for each case. The natural supporting partners of the person with dementia were identified and, where possible and appropriate, were actively involved in supporting the person with dementia. A limitation for two of the groups in the testing phase was the lack of representation of front line staff on the working group. This had been a deliberate action in the early phases of the work, as one learning site nominated a small number of representatives for the working group membership. The other group had focused on nominating management level representatives. One group felt challenged in the testing phase of the work as they shared that while they were the only ones within their colleagues in normal practice with a personalised lens from working in the group who could share the learnings of this pilot with their colleagues, they felt that wider contributions could have been made by their colleagues if they had been more deeply involved earlier. The second group addressed their challenges by working with their colleagues on the ground and inviting them to share their feedback directly to the wider working group during one of the meetings.

Additionally, the core ethos of personalised supports is that everyone is considered on an individualised-needs basis. Adopting this approach, the groups aligned to the belief that there should be 'no barrier to entry' for people with dementia. Therefore, there were no entry thresholds, limitations or criteria set for the cases to be tested by the groups other than that the person had dementia.

5.3.4 No Condition Severity Entry Limit

Adopting a personalised approach to care delivery meant that the approach was *"criteria free almost"* (WG2 M#5). All groups, in deciding which cases to test, felt strongly that personalised supports had relevance across the continuum of dementia (i.e. testing across mild, moderate and advanced stages). There was no 'condition severity' limit to entry. While all groups reflected the appropriateness of a personalised approach to care for all stages of dementia, they advocated for engagement at earlier stages of dementia and to build incrementally as needs change and progress. This would ensure that the person is supported to be as able as possible at any given point in their journey with dementia. It would also enable easier introductions of support at a point in the person's disease when they have an awareness and ability to engage in the supports they are happy to receive. Trust is therefore built before additional supports are required.

The key aspect of a personalised approach to care is the inclusion of the person with dementia and their primary carer in the design of supports. The exclusion of either party in the design phase can contribute to an unsuccessful implementation of support. The groups found this acroos all stages of dementa.

> *"We've actually got a spectrum, we've got the people with earlier, younger earlier dementias that really can use the intervention in order to stay home long term and then at the end of the spectrum you've got the carers who are so burnt out, but they could stay home a lot longer if there was a personalised approach, so there's kind of a continuum there in terms of the right people".* (WG4 M#5)

While all groups tested at all stages of dementia, one group tested cases on their waiting list for DSIHCPs addressing those with significant care needs. The highest level of support provided in this site was 27 hours per week for a person with dementia.

5.3.5 No 'Need Restriction' Entry Limit

In addition, sites wished to bring to the fore cases that had social support needs rather than physical or personal care needs only. Participants strongly advocated for the needs of these individuals to support their current ability. This contrasted with the traditional model where these support needs could not be met. Therefore, for the cases tested, there was no 'need restriction' limit to entry.

5.3.6 Constituent Parts of a Personalised Care Plan

In reviewing the cases tested, participants reflected on the constituent parts of the care plans designed for people with dementia in the live-testing phase, which were as follows:

- ➲ Supports designed with the person and their family in an open and collaborative way that enabled the meeting of actual rather than perceived need.
- ➲ Supports not confined to paid supports only, but rather filling the gaps by drawing from the natural supporting partners of the person with dementia, which included the family, friends and neighbours, the community and finally health and social care.
- ➲ Cost-effective supports .
- ➲ Supports provided in the home and outside of the home depending on the person's needs.

- ➲ Supports incorporating physical, personal and psychosocial supports: recognising that people with dementia will have multiple needs and in some instances maintenance of connection and ability rather than a physical need will be to the fore.
- ➲ Supports meeting the needs of both the person with dementia and their primary carer: Supports need to be mutually beneficial to both and delivered in a purposeful and outcome-focused way.
- ➲ Supports with flexibility and responsiveness incorporating day, evening, overnight and weekend supports and, where appropriate, incremental increase over time.
- ➲ Personalised supports enabling hospital discharge, avoidance of premature long-term care, and support to end of life.

The following quote reflects a participant's viewpoint of what was different about a personalised approach to care:

"I think it feels a lot more flexible and open and creative, I suppose so, and very much more individualised and more meaningful to that person. It's what's meaningful to this person and what's going to make life better for them, rather than this is all we've got, take it or leave it." (WG2 M#5)

One limitation of the process of testing and implementing a personalised approach related to the application and approval process that had been pre-determined for the pilot programme. It was deemed to be prohibitive for cases that required low numbers of hours, or for cases requiring approval of funding for anticipatory care. Many participants have shared their belief that such budgets should be held locally to facilitate a timelier response.

6.0 Outcomes of Working in a Personalised Way

The outcomes of testing a personalised approach to care are described from the perspectives of the working group members in the following section. All groups were asked to consider the outcomes they achieved through the lens of (i) the person and their family, (ii) frontline staff and finally (iii) service management.

6.1   Impact on the Person with Dementia and Family

Groups reflected on the impact of working in a personalised way from the perspective of working with family members. Family members' feedback to the groups reflected "relief" that supports were now in place; a sense of feeling "heard" and "supported"; and that their only wish was to have received the supports sooner.

Another group shared their observations of how tailoring the support towards the needs of the person with dementia and their family was greatly valued and was reflected as being "nearly even beyond the expectations of the wife and the client and the family (WG3 M#5.) Of note is that the supports provided for this case were 3.5 hours per week. From the groups perspective this case would not have received support within the current home care service as the person did not have personal/physical care needs.

Identified need: Support with activities of interest and support for main carer.	Gender: Male	Dementia Diagnosis: Mixed, moderate

Presenting Need: 82 years old. Lives with wife, has five children. Wishes to return to mass and go out walking. Has lost confidence because of falls. Family help with personal care. Attending day hospital but will be discharged soon. Has become less interested in things, not able to follow conversations, requires prompting to eat. Visual impairment. Experiences depression and anxiety. Likes walking but getting lost recently. Wife stressed when leaving him alone (every second Tuesday). Family concerned about wife stress.

Supports implemented: Support worker to assist going out walking and attending mass. Referred to physiotherapy and Occupational Therapist. NCBI being re-engaged by daughter.

Total package: 4.5 hours block hours a week – 3.5 hours alternate weeks. Cost: €130.81. Purpose and objective: To support gentleman in activities of interest such as walking and mass and reassure his wife that he is safe when she is not with him. To provide respite opportunity for wife.

Update: A male carer has been provided to this gentleman, working well, providing support with walking, household chores the gentleman is interested in, and personal care such as shaving.

One participant describes below the shared views of many participants that a personalised approach values the person with dementia as a unique individual and supports their quality of life.

> "Gives them a sense of value and quality of life you know like we're putting in all these supports and we think oh that's great you're up, you're washed, you're clean isn't that great, you can sit in the chair for the day but actually their sense of who they are ... Now (with this) they're able to get out, they're able to do things that's important to them which improves their quality of life and in turn keeps them well". WG7 M5#

Designing with the family provided instances where the support hours requested were not high even for cases that would have been quite complex.

> "It identifies the hours that are actually wanted not the bulk that's being sought from the initial stages, like coming in within this 21 hours straight off and, as [another member] said, if it's more personalised it's actually meeting the needs of the individual and, as you said, there is usually a reduction because it's very specific to that individual and what they want." (WG3 M#6)

One participant shared how, for them, designing supports with the person with dementia enabled them to move beyond discussion centred solely on personal care. In doing so they developed a richer understanding of the person with dementia.

> "So it was very interesting with [the patient] to sit down with him and figure out what else he does in his life besides showering and going to the toilet, do you know what I mean?" (WG4 M#4).

Another participant shared how the person with dementia "dictated the whole thing as to what she wanted." (WG3 M#4)

Both examples reflect the ability of people with dementia to engage in the design of their own care plan. A caution, however, from one of the groups was the need to support this engagement where appropriate with functional assessments that ascertain the ability of the person with dementia to engage in specific activities.

Group discussions centred on how they felt this work had impacted the person and their family.

> " R1: I think it's a different approach and a different way of thinking. So, I think including the family and mapping out what's important for them rather than us prescribing it's a co-decision.
>
> R2: It's an enhanced quality of life.
>
> R3: They are doing stuff that is going to benefit them long term." (WG3 #M5)"

Designing supports with the person with dementia and family also highlighted instances of complexity. One participant shared how providing personalised support was probably sustaining a family involvement for a case where the gentleman was separated from his family. Working with other families also highlighted the real challenges they face in supporting their loved ones. For example:

- ➲ Acceptance of the condition itself, raising their expectations about what is possible for their loved one to continue to do.
- ➲ Letting go of an overprotective nature.
- ➲ Addressing their own beliefs about dementia.

⮥ Coming to terms with support staff entering their home and the implications for them as a wider family in their home environment.

Participants recognised that designing supports with the person with dementia and their family therefore needs:

⮥ Flexibility

⮥ Time

⮥ Access to different support types

⮥ An ability to incrementally increase supports

As described by one participant *"you can't rush in with people, so it needs to be quite personalised and really building into the acceptance of the package by the person with dementia and the carer."* (WG4 M#5)

The presumption that paid care is always the solution, or that family will be accepting of supports is reflected on in the following quote. A group reflects on their learnings in relation to a case where from a practitioner's perspective there was significant need due to family stress. Engaging with the family in a personalised way propelled the family to reflect as a unit on their support needs for their Dad and how they might be best met. A review of the person's support needs was undertaken, with a family decision that they as a unit would support their Dad, without paid support. This was a learning experience for staff as they grew to accept the equality of the triadic relationship between the person, family and practitioner in deciding the best approach for the person.

"…..it's also a learning for the service as well in terms of how we approach families going forward you know that if you take the individualised personal approach , keep that to the fore maybe the conversations you have are different rather than prescribing what you think somebody needs that we sit, and we listen a bit more." WG7 M5#

The following case illustrates the extent of family involvement prior to requests for paid support and highlights the need for a considered plan on how to support the primary carer who has been carrying the full responsibility of care for some time, and to consider the lady herself and how she may best be supported.

Identified need: Maintain ability, social engagement for client, support for carer	**Gender:** Female	**Dementia Diagnosis:** Type unknown, moderate/advanced

Presenting Need: Female, 86 years old. Lives with husband who is a builder and works from 7am-7pm. Husband prepares meals. Phones to remind her to eat. On her own by day, husband set up camera in the house. Daughter visits weekly. Two other children from previous marriage. Has been some instances of wandering. Likes singing. Managed well until two years ago when daughter left home. Pressing needs are lack of social stimulation, nutritional needs, safety considerations and assistance with meals. Husband distressed. Needs support in his caring role.

Supports implemented: 1-hour Mon-Fri in morning, 2 hours Mon-Fri in afternoon. 2 hours Saturday & 1-hour Sunday

Total package: 18 hours. Cost: €468.55

Purpose and objective: To provide purposeful engagement for client, support nutrition and support maintenance of ability. To relieve carer stress by providing respite.

Feedback from the gentleman in this case has been very positive as he sees his wife supported to continue with the life chores she had always undertaken such as washing and ironing clothes. This lady is now engaged in purposeful activities as the support worker enables her to continue doing these chores, by providing the right prompts to the lady and setting the environment up for her to succeed.

For some families, it took time to move from the traditional mindset of home care (meaning personal care provided in the home). As described by one participant, *"So even though I had the discussion about [it] - this is to allay the anxiety of being on her own all day and socialisation and getting out and spending time. They didn't seem to really... I think the general perception of what homecare packages provide, it still wasn't getting through."* (WG3 M#5)

In this shared instance, while the person with dementia was quite clear about the support they needed, time was required to build trust with the family to move towards a more personalised approach. One group identified instances where the timing of the intervention was too late leading to an unsuccessful intervention as the person's needs progressed and decisions for long term care were made. The key learnings from this group were that earlier interventions where the person, their primary carer, and their family can be involved is key.

The importance of 'timing' was also raised in another case whereby the individual's family relayed that the process had taken too long. An application for a HCP had been submitted earlier in the year and was revisited considering the pilot by which time the lady's husband was experiencing a high degree of carer burden. By the time the supports were implemented he was already looking towards long term care.

> *"One (case) felt that it all came too late, that the process was too long, that by the time they got the care it had advanced so much and they're the ones that are now looking for long term care.....and it's a balance to hear their need for long term care but also seeing if they stayed with the project a little longer, could she stay at home a bit longer..."* (WG2 M#5)

The process of designing supports collaboratively ensured that the person with dementia and their family could articulate their needs and be involved in creating the response to meet those requirements. This represented a shift away from directing care towards people based on "perceived" need and instead delivering this support within a framework of pre-set hours and personal care delivery. One group reflected that cases that would have been traditionally seen as being quite complex were being managed on very few hours.

> *R2:" when you go more towards personalised that maybe now they only need three hours, yet they would have been some of the cases [that] would have been traditionally seen as very, very complex and yet they're being managed by very little hours on the grander scheme of things."* (WG4 Group Meeting #5)

The following two test cases demonstrated instances where families, through co-design with the person with dementia and a health care professional, identified very specific needs that differed on alternate weeks. These examples illustrate the potential that exists in co-design of supports whereby families ask only for what they need. One case was a request for support for 3.5 hours on one week and 4.5 hours on an alternate week. For another case, the primary carer asked for support of 14 hours on one week and 22 hours on alternate weeks. In both instances, the context of need was very clear. In providing a respite opportunity for the primary carer in the first case, they could co-ordinate and align to commitments and interests that she had and was specific in requesting those times only. Supports provided for the person with dementia were purposeful and appropriate to the person with dementia. The primary carer in the second case was clear about what she could do herself or pay for privately and what family and friends could do, with the resulting pinch points of specific times within her husband's calendar identified. Providing the requested support assisted this lady in continuing to work.

Identified need: Reconnection to life interests and support for family carer.	Gender: Male	Dementia Diagnosis: Early onset Alzheimer's - Moderate.

Presenting Need: 64 years, wife is primary carer, feeling pressure, working full time, all leave options exhausted. No children. Client attends day care, long days here not helpful. Wants to be active and involved. Previous period of psychosis - threatening to wife. Client enjoys sports such as golf, football, swimming. Existing supports: 14 Alzheimer Society of Ireland (ASI) hours & day care x 2.

Supports implemented: 14/22 (Average 18) hours - to transition from day care to personalised one to one support, support wife to continue work and provide purposeful support for gentleman. Support gap on Saturday so wife can work, and alternative Sundays support for family. Existing ASI hours remain.

Total package: 18 hours. Cost: €578.85

Purpose and objective: To support gentleman to be active, reconnect to his interests, support maintenance of daily/normalising activities. Replace day care with personalised support with purpose of engagement in activities of interest such as swimming, grocery shopping. Provide respite wife and wider family.

In summary, a more collaborative and open engagement with the person and the family gave an opportunity for them to articulate their needs. This, oftentimes, resulted in a smaller request for support than would have been originally anticipated. Additionally, there was greater recognition that the person and their family may need time to accept support. Giving them some time and a slow build towards support could assist them in making that transition.

6.2   Impact on Frontline Staff

"……. you kind of have to identify the personal care needs of someone who doesn't necessarily have those personal care needs, so it is, this is much better because it's working with the person and their needs and it's not just around their personal care per se." WG7 M5#

The above quote illustrates the fundamental shift in thinking to the fore of staff's engagement in assessing need in a personalised way. It illustrates how the focus in the past has been on trying to 'fit' a response that is limited in its scope to a 'need' that doesn't readily fall into that narrow band.

Some participants drew comparisons between the current home care model and testing personalised supports in the context of how they, as practitioners, experienced their roles differently in each model. One participant reflected that in the current home care model there was a lot of time spent "fighting fires" but her experience with testing personalised supports was that she was getting ahead of the crises. Another participant describes how even engaging in such a process was helpful at a time of resource constraints.

"So, I think it was great to have the opportunity to do this especially at a time where there are no resources, in fact it has been my light." (WG8 M#5)

Participants also reflected that, for relatively small inputs, they had been able to make a real difference by providing personalised supports. They valued seeing the person living their 'normal' life whether it be out in their community being supported in undertaking their daily chores such as shopping or going to the hairdressers, or in the home supported to continue their life roles. One such example is the case below which supported a lady to continue in her grandmother role of providing a snack to her grandchildren in the afternoon after picking them up from school.

Identified need: Maintenance of activities and supported engagement	Gender: Female	Dementia Diagnosis: Young onset dementia.

Presenting Need: 66-year-old female. Lives alone. Has insight into her dementia. Gets frustrated re speech difficulties - decreased communications skills since diagnosis. Recently accidently 'overdosed' on her medications. Need for socialisation – interest in getting out more, very sociable lady. Has one daughter. Collects daughter's children from school a few days a week and spends time with them before daughter returns from work. This is very important to her.

Supports implemented: 1 hour in the morning x 7, 3-hour blocks x 2 days

Total package: 13 hours Cost: €340.30

Purpose and objective. Support with medication management. Companionship and engagement for client. Support to continue collecting her grandchildren i.e. safety considerations- somebody to be present when she returns with children and assistance to prepare light snack.

Another participant considered how her role in the current home care model is influenced by fixed mind-sets that place barriers in front of doing things differently. In testing a personalised support model, she became reflective of what she could do to re-engage and re-evaluate a person with dementia whose needs were progressing.

Grounding the programme in experiential learning has provided opportunity for the groups to test personalised supports as a home care response in a real way, whilst also providing opportunity for reflection at an individual level in a way that can inform ongoing change.

A further example of how participants experienced their roles through this process was the transfer of learnings from testing personalised supports to incorporating them into their job in normal practice. One participant describes how being involved in testing personalised supports as part of the working group meant that she now undertook assessments differently in her job. She is now bringing the care and support elements into her discussions with the person with dementia and their family. The participant found this a helpful resource as it assisted her in eliciting more information about the existing supporting partners for the person with dementia and how they could contribute to supporting the person with dementia.

Other participants were able to identify valuable learning that they wish to proactively transfer to their job. An example shared

was of how several participants valued the paperwork provided to undertake personalised assessments. They sought out opportunity to work collaboratively with others to bring that into their practice. Other participants also formally shared their learning from the programme with colleagues from their discipline.

Participants reflected that the process did not require

"too much extra work, but it actually made the work very much more meaningful... in terms of what [we] could do". (WG3 #4)

Participants shared how they experienced personal development through the process and job satisfaction in

"see[ing] the change and the signs in their family, the benefit for them... It's like, wow, it's actually making a difference, you know." (WG1 M#5)

At a personal level, participants reflected on how they enjoyed testing personalised supports, sharing that they found it to be an "exciting", "enjoyable" and "refreshing" way of working since it provided them with the opportunity to flexibly meet the needs of people with dementia and their families. The following quote is an individual reflection as the person considers the impact of working in a personalised way on their own practice.

"I remember the second or third meeting we had after I put in one [case] saying I used to think I did really good assessments but now I realise they could have been a lot better and I think that's a really good piece." (WG2 M#5)

Overall, staff shared a sense of job satisfaction as they created a response to the challenges they faced daily. Their input into the fabric of the personalised approach adopted by the group meant that they endorsed the vision and actualised it on the ground. All have reflected that the person with dementia's quality of life was improved and that their own experience of being involved was a positive one.

6.2.1 Integrated Working as a Mechanism to Support Quality of Care

Groups shared the benefits of working collaboratively. For some, the benefits related particularly to live case testing of a personalised approach in practice as it wasn't about the level of home care provided but rather the input from all the disciplines that had provided quality of care.

Group decision-making and consensus-seeking about the cases going forward for implementation was also valued as multiple inputs and perspectives were shared. The value placed on this approach was particularly poignant in an environment where people can feel isolated in their decision-making and holding of cases in the community.

A number of groups proposed such a forum as beneficial for practice generally, with one participant sharing, *"...I think as a way of working, and irrespective of how we go forward, that it has to be that kind of shared [decision] and just keeping the patient centred with PHN, acute, you know all the different levels that we have here."* (WG2 M#5)

Other participants reflected how, as a discipline or service, being around the table was a "huge shift" as they would not normally have been part of a process relating to home care case discussion. Being part of the process and seeing its potential for achieving better outcomes for the person with dementia was a positive experience for those participants. Groups shared their felt sense of satisfaction as they saw people actively engaged in continuing their life roles. This shift away from passive receipt of supports that focused on what a person can't do to purposefully engaging in what a person can do was highly valued by staff, family and the person with dementia. Examples include:

- ➲ Normal life chores such as shopping, collecting pension, mass, companionship through conversation, keeping relationships with family members, activities and interests such as puzzles, knitting, home chores such as ironing and hanging clothes on the line.

- ➲ Activities such as swimming to support mobility, walking, GAA club's social engagements, pub, bridge, art, choir, exercise.

- ➲ Social supports such as Peer Support, Cognitive Support, Lunch club, Day Care.

- ➲ Supports to maintain personal and physical care needs, medication and meal prompts.

A further benefit was a growing awareness among disciplines who were members of the working group of the contributions that

their discipline could make in supporting the person with dementia. Active participation in live testing was a positive experience for many with participants advocating for the opportunity to be part of the process in providing greater input to home care discussion.

Integrated working as an approach to supporting quality of care was discussed within the groups. While collaboration was key within the wider working group, further in-depth collaboration occurred with participants as they worked with colleagues collaboratively outside of the group environment in the testing phase of live case testing. They undertook personalised assessments and implemented personalised support plans collaboratively. Many reflected on the benefits of working with their colleagues and undertaking joint assessments as multiple insights and expertise were provided to a case. There was also a learning opportunity to gain a greater understanding of each other's work within that environment. It was equally shared that it was more time efficient as multiple visits were not required, benefitting the person with dementia and their family.

While integrated working is occurring in various ways across various sites with primary care teams and integrated care teams as examples, the approximately eighty group member participants across the eight sites have shared the above comments as their reflections of the benefits of group working and collaborative engagement to support a personalised approach to care. In all sites,

introductions were undertaken at the first meeting as all participants did not know each other prior to this engagement. At the end of the process many participants shared the benefits of working collaboratively with one simple benefit being how they now had contacts in other disciplines that they could reach out to for support when needed. Those who worked collaboratively to assess cases valued the shared approach, with one group advocating for this approach as the norm for assessment of need, because of the richness that is provided in the assessment and because of the efficiency it provided for the person with dementia.

Discussions about primary care access differed across the sites. For some, there was a felt sense that they didn't exist, or were 'virtual' and not tangible to access. For others, they were shared as the obvious place to undertake complex case discussion.

The value of collaborative working was acknowledged by groups, where it was found that the skills and knowledge transfer that took place because of working together on cases was 'huge', as were the learnings that took place around the table. They also highlighted the continuing fragmentation that exists within services more generally, particularly for complex cases. It was noted that an interdisciplinary, collaborative approach tended to happen very quickly and worked extremely well when individuals had reached crisis point but it was the belief of most that this process needed to happen for all cases.

Challenges to integrated working between the hospital and community settings had been raised by participants. Some groups reflected how the experience of being part of the same working group was helpful in gaining clearer understanding of the other perspectives and the challenges that they face in undertaking their work. One participant advocated for the continuance of such an approach to support a more integrated approach between hospital and community in their area. One case tested in a pilot site highlighted the need for further exploration of integrated approaches between hospital and community as the person with dementia transitions to the home environment. This challenge was the most reflected challenge raised by participants when discussing integration and collaboration.

Integration of approach was discussed in the context of developing personalised supports and transferring the intent of the care plan through the pathway of home care on to the provider of care. The cases tested were followed at each stage of the pathway through to implementation of care to ensure that the intent of the personalised care plan was realised on the ground.

This follow through was very necessary, as in some existing pathways continuity of information is not routine as described in the following quote.

> *"I think that actually your input and your conversation with the family gets lost in the traditional way completely……. you know no matter what amount of information you write which goes to home care packages and then its transcribed and then sent off to a third, another person, you know that information is lost." WG7 M#5*

Some pathways depended on home coordination staff receiving information from the person who undertook the assessment and then sharing it in another format with home care providers. Other participants described reaching out independently to providers or meeting with them to share how care was to be delivered.

Another group questioned whether national home care applications documentation needed to be adjusted to gain consent from the person with dementia to share such information. Transfer of information was key for personalised supports to ensure that the jointly-developed plan of care was implemented at the front line as expected.

The continuing value of integrated working approaches post-implementation was also spotlighted in discussions, particularly as it related to complex cases. The cases tested within the programmes were followed by the groups, with key personnel actively engaged in reviewing the cases and updating the groups.

This was considered particularly important within current contexts. One group observed how supporting the person with dementia on an ongoing basis required the input of more than one service or discipline. Some participants shared how cases were 'held' by home care when a broader integrated approach to supporting the case was required. They expressed that relevant and specialist supports needed to be accessible and that supporting such cases required a shared endeavour.

During testing the multidiscipline approach to these complex cases, limitations arose when all the key partners involved had not been active participants in planning and implementing that care. The risk of 'gaps' in continuity were higher in these instances. However, the system contains a failsafe in the form of designated personnel in the working group who had undertaken to follow the case through to continue being actively involved for extended periods. These designates were able to give additional input to maintain continuity of care. This example illustrated the need for a collaborative and integrated approach to care delivery for people with dementia.

6.2.2 Collaborative working as a mechanism to support change

Collaborating as a working group provided space to gain a greater understanding of each other's perspectives and frustrations. This enhanced-understanding strengthened the collaborative and integrated approach of the group as previously-held assumptions were challenged and a more balanced view emerged.

This improved awareness grew as group members learned about the competing demands that their colleagues faced, thereby realising that the 'system' rather than the 'person' or 'discipline' was their joint challenge to overcome. An example to illustrate this scenario relates to a conversation about allocation of home care budgets, with prioritisation given to hospital discharges. Disciplines working to support people to remain at home gained a greater

understanding of their colleagues who held the responsibility for home care approval and the competing challenges they faced. Through discussion they recognised that while both may advocate for the same thing (i.e. for the person to remain at home) the priorities that one discipline had to work within were opposite to that goal. The previously held frustrations of the 'person' or 'function' was collapsed as staff moved to a greater understanding of each other's challenges.

The outcome of this conversation was not going to be able to address the challenge of competing priorities, but it did break down some of the barriers that existed across disciplines and functions as they seek to work collaboratively towards a common goal.

Other assumptions or misunderstandings were challenged and clarified by colleagues and this brought a greater understanding and acceptance for decisions previously made in practice. For example, in a case there had been a previously-held assumption that a request for home care had been denied whereas it was discovered that the request had been approved but put on a waiting list. This helped clarify for one participant what had occurred for one of the clients that they had advocated for and dispelled some of the bad feeling that the request had been rejected without explanation.

Other instances provided opportunity for perceptions to be challenged, with a more balanced and normative understanding arising from the group's collective input.

One such example related to some participants' strong beliefs that families were challenging to deal with, as they wanted as many hours as possible. This generalisation was challenged by other participants as they asked the group to consider why families may be angry and frustrated. This provided an environment for a greater empathy with the families experience to emerge. It was further built on as comparisons between families' frustrations and stresses and staff's frustrations at working within constrained environments were discussed. This facilitated the group's reflection on the stress they experience in their role on an individual basis, with all recognising the need to support each other as colleagues.

In turn, the discussion also contributed to a more balanced view of the stresses felt by families. It is vital for key supporting partners working with families to overcome these perceived barriers if better outcomes for the person with dementia are to be achieved.

6.3   Service Management - Cost Implications

The emphasis for this programme was on the process and practice changes required to implement a personalised supports response within home care delivery and to develop an enhanced pathway for such an approach. It was not intended to be a cost evaluation or analysis of personalised supports as an approach to care. This question has already been answered within the broader programme which is the HSE & Genio Dementia Programme 2011-2018.

The purpose of allocating an amount of funding to each of the working groups was to support the real case testing of personalised supports in a live environment and therefore the funding allocation was small, and the overall number of cases tested per site was limited. The emphasis was not on 'how many' cases can be tested within that funding envelope but rather 'how can' a personalised approach to care be implemented within a live environment.

The funding allocated to each site was €3,000 (the equivalent of two intensive home care packages at €1,500 each). As this equates to a relatively low number of cases, no firm conclusions relating to costs can be drawn.

Fifty-nine cases were considered for testing within the working groups. Each group was invited to collapse temporarily into smaller sub groups and to seek cases from their caseloads, home care waiting lists or DSIHCP waiting lists to bring back to the wider group for discussion. Through an action learning set each case was presented, questions for clarification were asked, discussions were had about how to support this person in a personalised way, and agreement was sought whether this was the appropriate pathway for this person with dementia to go through.

In total 41 of the 58 cases have been implemented, with further five pending as per table below.

Total Cases Presented	59
43 Cases - Live tested 5 Cases - Pending	48
RIP prior to implementation	1
Extended hospital stays pending LTC	2
Refused Support	4
Went to LTC prior to implementation	2
Other	2

Dementia Stages

- Mild - Mild/Mod - Mod
- Mod/Adv - Adv - Unknown

Dementia Type

- Alzheimers - Vascular
- Mixed - Fronto Temporal
- Lewy Body - Unknown
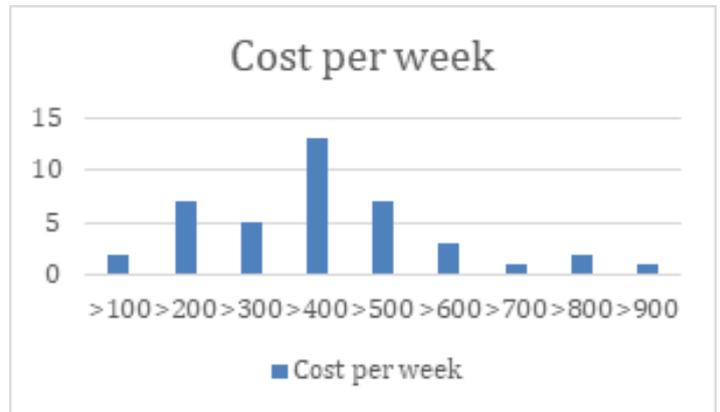
Cost per week

The above graph illustrates the number of cases against cost per week cost points of between 1-100 per week, 100 -200 per week etc.

Working group participants had shared perceptions that dementia care was prohibitively costly. One group reflected an awareness that over the past three or four years a significant number of their referrals to home care were people with dementia but there was a sense that support for these clients could not be provided because it would be too costly, and they would be 'swamped'.

Learning from the process of testing real cases has changed perceptions relating to cost. As one group reflected on the relatively low number of hours provided for several the cases tested, they shared the general feeling across all groups that 'bigger is not always better'. 'We've tried it, this works' was the message shared. They also noted that dementia presents a challenge for healthcare supports, with numbers high and increasing.
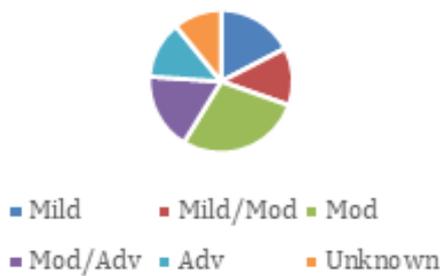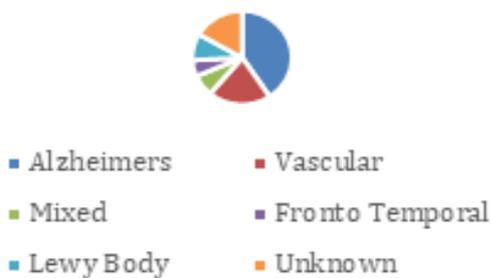
They felt that personalised supports are an effective approach and response to that challenge.

> *"And I think actually the experience of this has been proving the point that actually the three hours are every bit as important as the 42 hours. In fact, by the 42 hours you are beyond …what's sustainable, what's actually potentially workable." (WG3 M#5)*

Some participants felt that a personalised approach would be cost effective with some feeling it would be costlier as people would receive support that they otherwise wouldn't have using the traditional model. Conversely, with the traditional model some found themselves applying for more hours than the client needed as reflected by the quote below.

> *"……they're applying for seven hours because that's you know it's that or nothing and they might only need two or three hours during the week, but you have to apply for the seven because that's all you're going to get". (WG7 M#5)*

Cost savings and efficiencies were proposed by groups in the context of preventative costs as groups reflected that supporting now at a small level could positively impact progression and therefore support needs in the future.

Additional groups have also endorsed these findings as they reflected on complex cases that were supported with relatively low inputs. They also supported the argument that dementia is a presenting and growing issue and that a national focus on dementia care is required.

As work progressed with each group discussions on the cost implications of support predominantly related to the budgetary constraints that exist within the home care budget currently where demand outweighs delivery. When discussing whether personalised supports would be more expensive to deliver, the clear majority shared their belief that they would be cheaper to deliver. As the number of cases tested was relatively small in each working group, and the intent of the programme itself was to focus on process in developing an enhanced pathway for delivery of personalised supports rather than testing the cost-effectiveness of the approach which has already been undertaken in the HSE & Genio Dementia Programme, no firm conclusions should be drawn. All groups reflected that personalised supports were relevant to home care and should not be the sole domain of dementia care.

> *"Traditionally there has been a huge emphasis maybe on as [many] hours as possible, the quantity rather than the quality. And maybe through the learning of this I think it's shown that in certain cases it's not about the level of home care it's about the quality and the input from all the disciplines that really has paid off in a lot of these cases." (WG4 M#5)*

and

> *"I think one of the key learnings of this is that it doesn't take a whole lot of resources to get a personalised care package. It really doesn't, if you actually sit down and do it in that way, like you are saying a personalised way, looking at the support networks, looking at what is there in the community and then where the gaps are, you know really it doesn't take a whole lot." (WG4 M#4)*

The following quote reflects one participant's sense that while they cannot state categorically that personalised supports are cost effective, they can share their opinions based on the cases that they have tested in a personalised way.

"...I can't say hand on heart that it's less costly, but I can say to you that the cases that we [did] proved to be very cost-effective because we highlighted one in each area where they were certainly going to be in long-term care and they are now not. So that was certainly cost effective..." (WG1 M#5)

From another group's perspective, personalised supports provided an approach which could amount to cost savings from reduced hospital admissions and delayed use of long-term care.

"If it prevents hospital admissions, it's saving money. If it prevents someone from going into long-term care, it saves money."

"It's hugely cost effective...I think it wouldn't be rocket science for someone to take on some of these research projects to look at the kind of money that is being saved ... by spending a little bit now to prevent a lot in the future." (WG4 M #4)

From a cost perspective based on the test cases, groups reflected that personalised supports provided opportunity

"to be creative to meet needs that don't include huge sums of money". (WG4 M#5)

Among most of the groups, "additional" funding requirements to more broadly deliver a personalised supports approach within home care did not come to the fore. All would consider personalised supports as an approach that would not be more costly to deliver. However, for some, an initial injection of funding to develop requisite systems and teams may be required with the intent that there would be cost savings in the longer term. This is described more fully in the recommendations section below.

6.4   Case Discussion

A wide range of presenting needs combining different dementia types and stages, complexity and presenting needs were tested as part of the programme by each of the home care working groups. Case discussion in aspects of care needs that presented are shared in the following section.
While the number of cases tested is too small to draw any firm conclusions a number of the cases tested did address some of the more costly aspects to support for people with dementia.

Hospital Avoidance

Example: 20 Hours Support (5 existing plus 15 additional)

Hospital avoidance was tested by one group as they sought to explore how to assist a primary carer who was in crisis, caring for two parents including one with dementia. The primary carer had health needs also and there was recognition that hospital admission had been used in the past as a respite option by

the family. Due to the primary carer's recent ill health, all three (the person with dementia, their spouse, and the primary carer), were at high risk of further admission.

"I think as a hospital avoidance, this is urgent... It's a hospital avoidance for the three, well...for one and then the next two that go after her." (WG4 M#3)

To address this urgent issue a personalised home care support approach was implemented. The family was supported with short regular bursts of in home respite that supported the primary carer, providing relief in the evening to have some time away. The lady with dementia was supported to continue her interests within her own home. No further hospital admissions were recorded for this family at the time of work completed in this area.

The groups perspective on this case was that support and intervention should have been provided much earlier thus avoiding the crisis-driven responses that were utilised, hospitalisation in this instance. The importance of providing support much earlier for people was a key message shared by all groups.

Nursing Home Discharge

Example: 13 Hours Support

One test case supported a gentleman and his daughter. The gentleman was being supported in going home from a nursing home environment where he had been convalescing and long-term care had been discussed. His daughter wanted to be bring him home and was moving in with him to

support him because of his changed needs.

This significant transition for all involved was considered a potential risk for failed discharge and support for the daughter in transitioning to this role was considered valuable.

Thus, supports to inform this person's role as primary carer were provided as part of the overall package of supports. The daughter shared some feedback of her experience of being supported in a personalised way particularly in relation to support groups and learning about dementia.

"Very useful, I would recommend it for anybody. I think it was called the Family Carer's Programme or something like that, it was good. And then through that there are randomly other things come up, like something came up in [a school] on legal aspects of power of attorney and that kind of thing. I went up to that one Monday night and that was good. Again, it was informative." (WG3 I1)

Premature Long-Term Care Avoidance and Hospital Discharge

There were several test cases that were judged to be likely to progress to long-term care without intervention. They were cases with very limited or no family input, which added another level of complexity. Additionally, the people surrounding the person with dementia, whether it be family or neighbours (and even in some cases staff) were advocating for long-term care while the client wished to return home.

These cases were challenging for the participants involved in case testing. They raised issues such as risk and how this might be addressed; the need for regular reviews; and the importance of integrated working within the community and between the community and hospital to support the ongoing progression of needs for this person.

Example 1: 24 Hours Support (12 existing + 12 additional)

Example 2: 12 Hours Support (3 existing + 9 additional)

Hospital discharge as a topic raised two issues across most of the groups. The prioritisation of hospital discharges within homecare budgets was perceived as having the negative consequence of precipitating hospital admission in the first instance from the community. This was due to the lack of remaining resources available for cases in the community once hospital discharge priorities had been dealt with. Group participants felt that this prioritisation for hospital discharge was counter-productive and needed to be addressed with equal emphasis required for hospital avoidance by supporting people to remain in the community.

Many participants also perceived that the person with dementia would be best supported with an interim package to support hospital discharge. They shared that the person could not be appropriately assessed within an unfamiliar environment such as a hospital setting and should be followed up promptly with an assessment in the community to ascertain their actual needs. A number of participants felt that this aspiration was not being reflected in their area.

Several participants perceived that this emphasis on hospital discharge was providing high support levels, with the figure of 21 hours referenced regularly as the 'package' of care for discharge. Staff shared their belief that in some instances smaller amounts of support were more appropriate. They felt that reviews were important, and not always happening, and in an environment as previously described where there was a lack of trust in the system by some family and staff, there was a reluctance to reduce such hours for fear that they would not be available when needed. Review teams, where available, were considered valuable in supporting such cases. Equal weighting within budgets to hospital discharge and community support was also advocated for.

Early Intervention

For many of the groups, providing early interventions or preventative supports for people with dementia at early stages of their dementia was vital. As one participant reflected,

> *"I think there is huge opportunity for cost efficiency certainly [in] the long run and the short run." (WG4 M#5).*

Several the cases tested for this category also had younger onset dementia and as such accessibility to services under the current home care model would have been quite limited.

The working groups believed that it was important to highlight these cases because by providing supports at the earlier stages of dementia premature decline could be prevented for longer and certainly avoid

crises in the future. As described by one participant,

> "one to two hours a week is so much more important early on because it builds the trust, it builds relationships. It keeps them, the clients, independent for much, much longer and out of hospital and out of the whole cycle for much longer" (WG3 M#5).

Within a home care model that currently addresses only physical and personal care needs, it is felt that this group will not have their needs met in an 'honest' way. Some share the perception that the prevailing culture is that you must include a 'personal care need' for a person otherwise you are not going to get a home care package. Others share that these clients will not receive a support within the current prioritisation lists where there is a waiting list as they will be low priority. They also share how the prevailing message is that home care is about personal and physical care needs with social needs the exception.

A shift in thinking with an 'honest' approach to assessment that meets actual needs was considered by many participants to be one contribution to using existing resources more efficiently. This combined with the belief that a personalised approach resulted in a lower request for support than might be anticipated, and the identification of other supporting partners who can provide some of the input rather than services providing it all, are all concrete contributions to using existing resources prudently. The following quotes reflect one participant's reflections on this topic as they relay their experience of delivering DSIHCP in a personalised way.

> "When you're having those in-depth conversations with people it then can become clear what other supports are there or what other resilience's they have or other things to draw from that you wouldn't have known unless you gave them that time". (WG8-M#5)

> "Yeah I've been surprised with people's reactions to that. Where you think or you feel they're going to be looking for every hour under the sun and then you speak to them and they go really if I could just have four hours here we will manage with that because this, this and this and I've been very surprised because I would have expected these people to have been looking for an awful lot more" (WG8-M5#)

One case example demonstrated that for a lady with younger onset dementia referrals to supports such as cognitive stimulation and peer support possibly would not actually have happened in the current model. This is because she needed support to attend services and this would not have been provided.

A relatively small amount of support was also necessary for family members in supporting them to continue to be the primary carer of their loved one. By providing supports earlier and in small increments, "you can let the carer get back into some sort of a life of their own" (WG3 M#4). This was shown to help them to continue in their caring role for longer.

Another participant shared how focusing only on intensive or high-priority needs was *"missing the point"*. It was felt that home care

would *"end up costing more in the end"* if focus was not placed on positively impacting the progression of dementia. Intervening earlier, delivering supports that enable maintenance of ability and connection to the level of the person's current ability, being ability focused rather than deficit focused, supports avoidance of premature decline and avoids premature acceleration of support needs. (WG3 M#3)

While people with dementia are high users of home care, there is also a category of people with dementia with support needs who currently would not receive home care because they do not have physical or personal care need. Participants advocated for this group, believing that small supports earlier in the journey of dementia can support avoidance of premature disability.

While cost effectiveness was not a focus for this programme, it is appropriate to reflect that the key messages relating to cost reflect the findings of the externally evaluated economic analysis of a Community Based Model for Dementia, which used a personalised approach to care delivery. See www.genio.ie/economic-analysis-dementia.

See also Report 1, titled *Supporting Older People with Complex Needs at Home: Evaluation of the HSE Intensive Home Care Package Initiative* (Keogh et al 2018) which can be found here www.genio.ie/dementia-report1-ihcp. Cases tested have illustrated how a person with dementia can be supported well to

live at home for longer. Additionally, some cases demonstrated that progression and complexity of care needs could ultimately result in long-term care. Collaborative working among all the relevant stakeholders were key indicators for success in such cases.

7.0 Implications for Working in a Personalised Way

While there were limitations to the scale and reach that could be achieved within a pilot programme, working within a live structure of the current home care model has facilitated the emergence of new learnings about how to deliver a personalised approach to home care.

Testing within a live environment has, for the first time in Ireland, trialled a personalised approach to care delivery within existing live systems and services. This has provided an opportunity to review existing pathways for home care. It has also allowed occasion to identify the critical points in the pathway that require adjustment and enhancement to support implementation of a personalised approach to care delivery more broadly.

As participants reflected on their experiences of working in this way, they were asked to identify the prevailing challenges that exist in current practice that would need to be addressed or enhanced to fully support a wider application of personalised working within home care.

7.1   Knowledgeable and Informed Workforce

Dementia support skill levels are varied across sectors, disciplines and services. This was a limitation for the work of the groups as they could not direct allocation of specific dementia-skilled staff to specific cases since providers could not be selected by the group within current home care packages tender processes.

The introduction of the National Homecare Worker Dementia Education Programme is timely and should contribute significantly to addressing this challenge particularly if undertaken in a targeted fashion in these areas. It would seem there is potential to strategically engage in a coordinated way with resources such as this programme and the PREPARED programme (which has been developed to support primary care teams about dementia) to achieve scale in creating a dementia-informed staff base in a time efficient manner.

For some groups, discussion about educational supports for the home support worker particularly intertwined with the value the system places on the role of this staff member. As one group illustrated, the person with dementia and the paid carer

> *"are the two most important people and yet how that's valued, how that's nurtured, and particularly the carers in terms of how they are funded etc., has to be looked at". (WG3 M#5)*

This comment in the current environment of staff shortages and attrition, notwithstanding the significant cost implications, nonetheless has real implications for the future of healthcare delivery if not addressed.

Most groups recognised that while training in dementia was needed, a change in mindset about how to deliver services was also needed.

> *"So, you're talking about having that different mindset but that doesn't come by itself that's a specific education and training to do that ...." (WG2 M#5)*

While groups variously discussed whether a dementia skill can be taught or whether people just *"had the knack"* (WG2 M#5) in knowing how to support a person with dementia, the primary focus was recognising that the person with dementia will encounter a wide array of disciplines throughout their experience with dementia. Good dementia care was perceived as the responsibility of all services and disciplines. Therefore, a focus on raising awareness about dementia and personalised supports across the wider staff base is vital.

When discussing the wider and current landscape, consistency of care was felt to be challenging in the present climate of staff shortages and attrition. Consistency of care was also discussed in the context of dementia supports and intensive supports. As one group reflects,

"there will be other companies and in the space of three, four, five, six weeks they could have on a 12-hour package where they could have seven, eight, nine, ten different staff go through that door." (WG3 M#5)

These are real challenges being felt in service delivery currently. Groups reflected that this could impact on the success of home care delivery and quality of care for the person with dementia and their family. Ultimately, it could contribute to failed home care scenarios.

Additionally, the volume of agencies and providers to be engaged with was an impeding factor to personalised supports. The terms in which the HSE interacts,

contracts, and holds external agencies to standard was perceived as requiring substantial change. Some of these perceived challenges may be addressed with the new home care tender process and the rollout of a national home care module that is accessible to private providers. One example shared is the lack of case uptake by some providers, leaving a sense that the actual real number of providers in an area is lower than the approved tender list would suggest. Another example shared included a division of approach that can exist between the approval of the home support and how it is actually applied on the ground.

The chief message is that informed staff, knowledgeable about dementia and how to support a person with dementia, is crucial. While the home support worker is a role that should be valued as a key supporting role, the person with dementia will need to access many supports throughout their trajectory and therefore an informed and skilled staff base is vital.

7.2 Adoption of a Personalised Ethos to Care Delivery

Knowledge of personalised supports as a concept was also highlighted as necessary to deliver personalised care, particularly in relation to assessing needs through the design of supports with the person with dementia. Some participants reflected that nursing staff particularly needed to receive information about how to undertake this work. Equally for this approach to transfer through a system to the point of implementation, home care coordinators and providers would also need to receive information on this approach.

Some participants discussed how they had begun to share processes with colleagues. Other participants suggested an appropriate response would be for working group members to lead and share their learning of personalised supports with their own disciplines.

However, participants also shared their concerns about the risk of reverting back to 'traditional' approaches as they continue to work in a traditional care model environment.

The successful implementation of a personalised approach to care is dependent on an informed staff at assessment, approval and implementation stages of the pathway of homecare.

7.3 Further Develop Community Resources

The findings from the pilot programme have brought to light the potential for the supporting partners of family, wider social networks, community, social care and health to collectively support the person with dementia. While the groups could identify potential supporting partners in the community, such as groups, clubs, services that the community at large engages with, the limitations for the pilot programme was the under-development of these as spaces that were inclusive of people with dementia. Having tested personalised supports, all sites have identified the need to develop such an infrastructure in each area. This of course reflects and aligns to the awareness initiative of the Understand Together Campaign and the more recent Community Activation Programme, currently being developed. While all groups considered potential groups to engage with and invite onto the

working groups in the design phase of the pilot programme, only two groups invited members that sat outside HSE structures. Other groups added additional members to the working group, but these were HSE staff. While groups could identify additional representatives that might be helpful to the work of the group there was some hesitancy in moving to actual invitations due to several reasons. For some, time was needed to absorb the process themselves and it was perceived that additional representation was being considered too soon in the process. For others there was wariness in inviting one representative of a service and not others as it could be perceived as inequitable. Learnings from a facilitative point of view was that realisation of the importance of this representation to the working groups was in the main only realised after the groups had tested the personalised approach which required them to think about potential supporting partners within community and mainstream services. Having tested the approach, a clearer picture of who could be members, what they could contribute, and how they might be engaged with became clearer.

Group participants have identified key representatives to be invited to join any future working group to support further access to normalising community resources and services for people with dementia. Building awareness among these potential supporting partners could enhance the opportunity for people with dementia to be supported in their communities for longer. These representatives include community connectors such as development officers who within their roles have a broad reach

to appropriate services and resources. A targeted and collaborative approach to building dementia-inclusive communities is considered a valuable contribution to the support plan for people with dementia.

7.4 Coordination and Implementation of Care

Complex case discussion and coordination of care, as well as the promotion of a personalised approach were identified as key functions that would be required to support the development of integrated personalised services for people with dementia.

While some groups identified the need for a specialist role to be developed to address complex case discussion and care coordination, a smaller number of participants felt that personalised working was the remit of all practitioners.

Other options discussed were to situate complex case discussion within the environments of existing multidisciplinary teams. This was perceived as challenging for some participants as they shared how primary care teams were not functioning in their area.

An additional challenge raised in relation to continuity of care was the question over where a case would be held in the community, particularly where there was not a clinical need. While primary care was considered the appropriate place, the main messages shared by the groups was that a multidisciplinary approach to care, particularly for complexity, is necessary.

7.5 Perceptions of Risk in Supporting a Person with Dementia

Practitioners reflected on how supporting an individual to continue with ordinary life roles and activities in the community helped to normalise life for the person with dementia. Other participants reflected the benefits of being able to move beyond a 'risk' adverse approach to focus more on the care of the person with dementia.

Many practitioners viewed community integration as an essential component of personalised supports. However, in practical terms, there were perceived barriers to making this a reality. Groups brought forward the perception of risk in taking a person with dementia outside of their home and the need to have policy to support that action. For some, as the provision of support was delivered by private care providers for the pilot programme, any insurance considerations were met and thus going outside of the home was not perceived as a problem. All groups felt that HSE home helps would not be able to provide out-of-home support due to limitations caused by current insurance cover. For the purposes of live testing within the pilot programme, as per the DSIHCP pathway, only private providers were used to deliver supports.

Staff reflected the need to have direction from an organisational perspective on the scope of what could be undertaken. For example, while groups shared their belief that HSE home helps could not provide

support outside of the home, many could not reference documents that stated that this was the case and instead tended to reference incidents that had occurred historically as the reason people could no longer be supported outside of the home. Discussions with some private providers at the "existing landscape" stage of the wider programme referenced their willingness and openness to providing this support, but not being asked to do so by the HSE.

Traditional perceptions of risk for people with dementia were challenged, with participants questioning the risk to the quality of life for the person with dementia in being in a risk-adverse environment. One participant observed,

"It's about us adjusting ourselves to our attitudes on that and our fears around it and… this idea of always keeping someone safe and warm and… if that means institutionalising them versus what they want." (WG4 M#4)

While there was a growing recognition that changing perceptions and mind-sets to adjust to a more positive risk-taking approach was required, for many this was perceived as challenging. Most saw the solution to risk as being a multidisciplinary decision-making process to mitigate against the perceived risks.

Others reflected that shared decision making was key with the inclusion of the person with dementia, their family and the health professional with an openness and clarity

about the risks that remained and consent to proceed in the knowledge of the risks involved.

Family perceptions of risk were also discussed with participants sharing how the prevailing stigma that exists with dementia, as well as the continuing lack of awareness of supporting the person to keep doing things for themselves was challenging for families to overcome. Education and awareness raising for families was discussed as a necessary approach to supporting a more positive outlook. It was also recognised that this change in attitudes would take time, could require ongoing engagement over a period to support a changing mind-set.

Risk as a topic was challenging for many who felt they held cases alone in the community. Most felt that positive risk taking was necessary to support the person with dementia to live well and required appropriate risk assessments with shared decision-making processes.

7.6   Leadership and management of this work

As the groups reflected on how personalised supports as an approach to care could be implemented in practice, a key discussion point was leadership and management of the process. Time and resources, as well as a level of autonomy to plan, develop and implement such an approach were key. To do this well, staff reflected the need for commitment and buy in to this approach from the outset from national and local senior management.

Several suggestions were proffered to promote and lead on such an initiative. Some groups shared that their forum with a broadened representation of stakeholders could be a central lead on the promotion and implementation of this approach in their area should there be any wider roll out of this approach to home care. Others suggested that developing specialist roles to coordinate complex case discussion for people with dementia were key and that promotion of a personalised approach to care should lie with them.

7.7   Process and Practice Implementation

The pathway of current dementia-specific supports has been mapped in each of the eight sites. A review, post-implementation of live test cases was undertaken to identify points in the pathway for adjustment or enhancement to incorporate a personalised approach to home care. See Appendix 3 for example.

The enhancements required related predominantly to the importance of transferring the information captured at assessment stage, bringing that through to the approval stage so that home care co-ordination was able to get a full sense of the needs of the person and be able to translate this information to the service provider and ultimately care worker delivering the service. The importance of such a mechanism was illustrated in each site as they shared the varied approaches that currently exist within home care services in translating the assessed need identified to a care plan of delivery. As shared by some staff, the richness

of data captured at assessment stage is not reflected on the home care application form. Therefore, some of the information is already lost by the time it arrives at home care co-ordination. In some instances, the detail is further distilled by home care co-ordination as the request for support is forwarded to the service provider. It is possible that the needs are further distilled between the provider and the care staff delivering that support.

A key component of the personalised approach is that the support is co-designed with the person and their family at assessment stage, it is imperative to the integrity of the approach that their assessed needs are met as they have identified.

i.   Assessment Stage: Personalised Assessment Form – that reflects a personalised approach and moves away from a tick box approach. A supporting narrative that assists staff in undertaking a personalised assessment is also advocated for.

ii. Approval Stage: Transfer of Information – a personalised assessment form that encompasses the psychosocial needs of the person that is goal focused accompanies CSAR through the pathway towards implementation.

iii. Implementation Stage: A care plan developed as part of the assessment process incorporates the support required, its purpose and objective, and how it is delivered.

While these points in the pathway have been identified, with some resources developed

to meet those enhancements, such as enhanced assessment forms and care plans, further work would be required in this area to formalise the process of information transfer.

7.8   Resource Allocation

During the programmes timeline, changes occurred within the home care service incorporating a move towards single funding which combined the traditional home help and home care services and budgets. Additionally, there was an introduction of consumer directed responses as an option for home care, whereby family could apply for home care to be delivered at times suitable to them. The prevailing focus on: getting in and out of bed, dressing and undressing, and personal care such as showering, and shaving did not change and remains the focus of home support.

Groups discussed resource allocation needs for personalised supports. They did not consider this approach to be costlier to deliver. As groups considered the potential for personalised supports to be incorporated into home care services as the approach to care delivery, most groups did reflect the need to have 'ring-fenced funding' to support the implementation of a personalised approach to care. The 'ring-fenced funding' was always suggested to 'protect' a budget for people with dementia within a home care service environment that is budgetary constrained. For some groups, this was envisaged to be ring-fenced money from existing local budgets. For others additional funding was required. This additional funding was usually because of existing financial

constraints within home care delivery and its impact on delivering supports.

While many discussed creating 'ring fenced' monies to support implementation of personalised support for people with dementia, on further examination, there was recognition that a high percentage of the existing home care budget is currently serving people with dementia with anecdotal examples shared being 40% in one area and 70% in another area. This does raise the question of the usefulness of segregating amounts of existing budgets.

Transfer to personalised supports is not dependent on resolution of these constraints as this is an approach to care rather than a costly application of care. It could feasibly apply to every home care package being approved currently. How this might be undertaken is explored in Section 8 Recommendations.

Groups also reflected that any budget or amount to support this work should be held at local level. All believed that the existing processes for home care approval at local level were sufficient and should incorporate any additional funding allocated to such work. This was particularly referenced by groups from their experiences of accessing funding for DSIHCP from the (i) national initiative which sought deliver up to 500 DSIHCP's and from the (ii) allocated funding for the pilot programme. Both were found to be time-consuming and prohibitive for some. This was particularly reflected by some home care managers, managers of older person services, and general managers as they felt

the additional elements added to the pathway for approval were unnecessary.

A final point of discussion regarding resource allocation related to all groups' belief that personalised supports had relevance across home care generally and not just cases of people with dementia.

Groups shared the need to have a whole person approach to care that reflects the following components:

➲ Personalised supports should be designed with the person and their family

➲ A needs-based assessment incorporating physical/personal and psychosocial needs is required.

➲ Home care supports should have greater flexibility and include overnight, weekend and block support-hour options that could be responsive to changing needs.

➲ Supports should be available in and out of the home.

➲ Maintenance of a support connection and inclusion in the community should be emphasised.

➲ Respite supports need to be mutually beneficial to both the person and their primary carer.

➲ Supports are provided by family, wider networks of friends and neighbours, the wider community, social and health care

The aspiration of this goal would indicate that 'dementia' care and related budgets would not be segregated from home care budgets but rather the overall approach to home care delivery would adopt a personalised approach to care within the existing budget. How this might be introduced from a change management perspective is suggested in Section 8 Recommendations.

8.0 Recommendations

The HSE & Genio Dementia Programme (www.genio.ie/dementia-programme), which began in 2011, sought initially to innovate what a personalised approach to care delivery could be for people with dementia. A community supports model emerged from this work across nine demonstration sites (www.genio.ie/community-supports-model). The learnings and content from this initial innovation phase of the HSE & Genio Dementia Programme has infused the 'Developing Integrated Services that are Personalised Programme' as each of the designated 'learning sites' has sought to immerse a personalised approach to care within a structure and live environment to their local area.

Each learning site has used this learning to contribute to new knowledge, particularly in relation to 'how' to implement change that is pertinent to local context. As each site has taken this learning and tested it within live environments, being cognisant of process and practice enhancements required to support this work, capacity has been built in how to implement this work in practice. At all times within each learning site was consideration given to the pathway of delivery for home care locally and the points in that pathway that required enhancement to support a personalised approach to care. The progressive knowledge gained by each site in supporting change within their local home care delivery pathway, builds upon the already significant development, implementation and evaluation of personalised supports under the HSE & Genio Dementia Programme 2011-2018 www.genio.ie/dementia-programme and would indicate the next and final stage of implementation is adoption of approach into service delivery.

Innovation	Immersion	Adoption
Demonstration sites	**Learning sites**	**New phase**
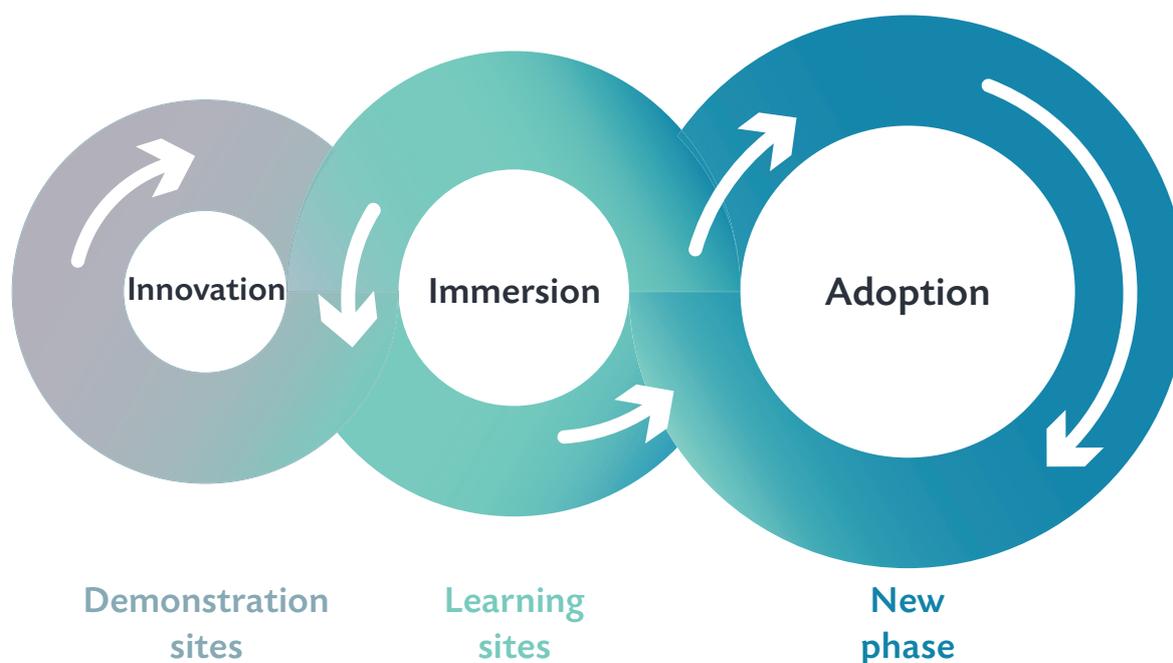
The learnings from this pilot programme reflect the findings from the HSE & Genio Dementia Programme 2011-2018 which are that personalised supports are cost effective, provide quality of life for the person with dementia and can support avoidance of premature long-term care entry.

The new learning added by the programme 'Developing Integrated Services that are personalised for people with dementia' has focused on the process and pathway elements of supporting a personalised approach to care delivery within a live system. This has been tested and been successful as an application to home delivery within 8 local contexts. All have been able to incorporate such an approach to home care to their existing pathways for home care delivery by creating enhanced processes and practices within that pathway.

Within this lens all participants, as active participants, also advocate for the adoption of this home care pathway for all home care recipients.

Pilot sites have clearly identified the points along their pathway of home care delivery that require adjustment, enhancement or additionality to incorporate a personalised approach to care. These incorporate procedural change, mind-set change or resource development and incorporate some very simple steps such as the development of an enhanced assessment form, as one example, to creating a pathway for home care that is personalised. Groups do caution against the supposition that these aspects can be taken as individual actions at local level and implemented in a fragmented fashion

into their local pathway for delivery. An example of this would be the introduction of an enhanced assessment that is personalised. While the assessment can be undertaken in a personalised way, approval of home care to deliver this personalised care would not currently be approved within the existing priority driven personal/physical care focus.

Change such as this is fragile, particularly when undertaken within the confines of a pilot programme. Fears about returning to the traditional mind-set were shared among participant. One participant shares such a concern in the quote below.

> *"I was just about to say we have no extra funding to keep that up, so you'll go back to the old mind-set .... Nobody has said that you can adopt this approach from here on in and we will find that hard," that was the really heart - breaking piece about all of this."* (WG2 M#5)

Progression of the implementation of a personalised approach to care requires the commitment of national and local management to a structured and planned programme of implementation that incorporates the following steps to achieving a personalised approach to home care delivery.

Establish National Protocols to Facilitate Transition to a Personalised Support Model

National support and input is required to facilitate application of personalised supports within home care delivery. The following aspects have been surfaced as consideration

points to be addressed within any programme or understanding of engagement at national level prior to implementation at local level.

➲ Commitment to the roll out of personalised approaches to home care for people with dementia or more broadly for home care generally.

➲ Development of a steering group at national level comprising local representation to develop national programme for implementation.

➲ Commitment to supporting such roll out at local level addressing resource implications from a human and financial perspective.

➲ The remit of home care transitions to a whole person approach incorporating psychosocial needs as well as personal/physical care need.

➲ Equal weight is given to psychosocial needs as well as the physical/personal needs a person may have to support a more equitable allocation of support within a home care environment where demand currently outweighs supply.

➲ Dementia skills are incorporated as a prerequisite for home care delivery within future home care tenders.

➲ Insurance considerations are revisited with clarity provided on delivering out of home support (HSE home help & private providers)

➲ Equal weighting of a) hospital discharges and b) community support as a preventative measure for hospital admission considered within a whole system approach.

➲ Collapse thresholds for entry to 'types' of home care to facilitate needs based individualised assessments that do not pre-empt or determine needs.

➲ All home care budgets are managed locally.

➲ Financial Resource - Agreement on allocation of budget for home care that is personalised is required.

    a. Utilise the full existing budget to support a personalised approach to care for all home care recipients.

    b. Ring fence an amount of the existing home care budget for specific groupings such as people with dementia to deliver a personalised approach to this cohort only.

    c. Provide additional funding to address the current supply versus demand challenges and adopt a personalised approach to care delivery within that.

➲ Human Resource - Commitment to support the development of local implementation groups in each area with dedicated time and specific resources is required.

    a. Dedicated clinical nurse specialist role to promote and lead on the development of personalised supports.

    b. Local implementation group to support the planning, development and implementation of a personalised approach to care.

    c. Allocation of specific supporting resources such as facilitation expertise, administrative support.

    d. Signposting as good practice approaches to existing or additional

resources such as: primary care teams, integrated care teams or review teams to support case complexity assessment and implementation.

➲ Facilitate cross learning opportunities across all areas involved in wider roll out of personalised services.

Establish Structures to Facilitate Transition to a Personalised Support Model

A development plan from a national perspective on the direction of home care services as it pertains to personalised supports would be a necessary requirement for local level adoption and implementation. Inclusion of national and local representatives in the development plan design phase at national level would be beneficial to ensure the 'design' can be implemented successfully at local level.

The following structures are necessary to support a transition to personalised supports:

➲ Rollout of this wider programme requires an overarching framework of implementation to be developed at national level with key stakeholder input that will comprise key action points towards implementing a standardisation of approach for all sites, whilst incorporating flexibility to facilitate individual local contexts.

➲ Develop a communication plan for all key stakeholders at national and local level.

➲ An intensive facilitation process is required to guide the relevant sites in their application of the work to be undertaken.

➲ A programme team of existing staff should be formed and equipped with time and resources to lead on the rollout for each area.

➲ An individualised implementation plan needs to be developed by each area to support rollout locally.

➲ A facility of engagement with national management to support centrality of approach based on a national development plan for implementation of a personalised approach to care

➲ Opportunities for shared learning and cross-fertilisation across all relevant programme teams should be created.

Implement nine core actions to support transition

The following core actions are required components of any programme of work undertaken.

➲ Deliver personalised supports awareness training to the staff base of nursing, home care coordination, and home care providers (HSE, Voluntary and Private).

➲ Deliver dementia skills training to front line staff.

➲ Explore and test opportunities for complex case discussion within multidisciplinary environment.

➲ Explore care coordination functions to support complex dementia cases at local level.

➲ Agree home care budget alignment to the work programme.

➲ Explore opportunities for the

development of a care and support network (incorporating family, wider social network, community supports and health and social care) in the community.

- ➲ Explore perceived challenges relating to out of home support provision or transport provision.

- ➲ Enhance the home care pathway and underlying processes and practice to support implementation of a personalised support response.

- ➲ Maximise existing and pending national initiatives that can be leveraged through coordinated efforts, to achieve greatest impact (e.g. national home help training to support increased dementia skill).

Position the Programme of Work within Primary Care Network Levels

Situating the programme in the appropriate space in the social and health care service to support best possible outcomes requires consideration. Should a further rollout of this initiative be considered, designated sites should cover a geographical spread that encompasses several the proposed primary care networks in each of the identified areas. Positioning the programme at network manager level would support this reach to several primary care networks. This is a suggested space; however, this is of course dependent on the systems readiness for change within that structure. As the following recommendations focus on the actions required to support such a transition, the key point with positioning is that they are strategically positioned within CHO areas at a level that can have a significant reach, such

as, for example, at local area level within the current CHO structures.

Situating a proposed programme within these structures is appropriate for the following reasons:

- ➲ This will be the future structure for community care.

- ➲ Any implementation programme will need to be able to align with and complement the operational structures that will have been developed.

- ➲ The membership of any programme team will need to be strategically positioned within that operational structure to have influence and impact.

- ➲ Supporting an organisational shift for home care requires the ongoing commitment and collaboration of, national stakeholder and at local level, (i) senior management of CHOs and heads of services, (ii) directors and senior managers of relevant disciplines and services, (iii) front line staff. The commitment and shared vision of all will be crucial in the adoption of a personalised approach to home care.

Proposed framework of implementation

A framework of implementation to inform rollout across all relevant sites creating a standardised implementation whilst remaining flexible to individual contexts is proposed. It is proposed that this framework is driven at national level, with clear leadership in rolling out the programme to each designated area that has been agreed by national management.

A facilitated engagement process has been advocated by some participants at local level to support the implementation team convened in each designated area to undertake this work.

The process of facilitation adopted would be intensive, solution-driven, and capacity-building focused. The key steps of the framework would include:

➲ Seek commitment and buy in to a transition of home care to personalised supports at local level. Engage with pertinent local level senior management. Identify and resource key leadership to for the implementation at local level and to work collaboratively with external facilitation. Identify and recruit key stakeholders across acute and community sectors for each site to an implementation group that has reach across some intended primary care networks.

➲ Build capacity of among the implementation team formed in each area to undertake the change programme of transitioning to personalised supports.

➲ Co-create an implementation plan with each team that addresses the core actions required to support this transition

➲ Create a forum to support cross-programme learning.

➲ Develop a template of implementation that will enable each CHO to independently apply the programme to the remaining primary care networks that have not been included in this second phase.

Effective Implementation Team Composition at local level.

Personnel involved across the home care pathway should be active participants in the actual rollout of the primary care network and the programme team developed to support organisational change so that all relevant aspects of process, policy and practice are appropriately addressed.

Situating the programme team appropriately to provide maximum opportunity for reach to primary care teams within the primary care network is vital. Creating such an environment in an operational structure that is transitioning to a primary care network structure in a phased fashion requires a flexibility of approach. It is necessary that any such environment of change can be created within:

➲ A team that comprises membership that will have reach across several primary care networks.

➲ A team that comprises members who will be retained and continue their functions when the primary care network is live.

- A team that can incorporate additional emerging representation within the primary care network structure.
- An implementation plan that is not dependent on aligning with the introduction of the primary care network but can be incorporated seamlessly into the primary care network structures when in place

Suggested Membership of the Programme Team Includes:

- Network managers
- General manager of social care
- Managers of older persons services
- Primary care managers
- Home care managers
- Directors of Public Health Nursing or representatives
- Allied health professional management or representatives
- Hospital representation from social worker or discharge coordinator

This core membership, at an appropriate management level, is key to ensuring that the relevant critical points along the home care pathway are addressed to enable transition to a personalised support response. It is important to note that many of the representatives noted above have already engaged in the pilot programme in each of the eight sites and are therefore key assets already in place. There is now potential to achieve change and begin to scale up by incorporating additional colleagues across those disciplines and functions within a broader representation in each area.

Additional Membership

Outreach to additional representatives or invitation to membership on the programme team is important to enable the development of appropriate, helpful and useable resources. Suggested additional representation could include the following:

- Service users and family carer representatives.
- Representatives from voluntary and community groups that attend to social care need
- HSE training and education infrastructures
- HSE quality and professional development representatives
- Key bridging resources to the community generally

This additional representation would ensure that the key actions as identified above are realised through collaborative efforts. For example, within a dementia specific context the need to develop dementia-inclusive community services was one message that came to the fore in the work of the pilot programmes. Community representatives, such as a community development officer with access, to and knowledge of, multiple groups within the local community would be a key stakeholder to engage with. Their established reach to these groups could support an efficient and scaled approach to developing a dementia inclusive community.

While the examples shared relate predominantly to dementia and older person, services, the actual membership will be dependent on each group's local context and remit for roll out.

8.1 Summary

The pilot programme undertaken has provided a testing opportunity to each site in developing integrated services that are personalised within live environments. The groups have provided cost-effective, quality-driven personalised supports for people with dementia. They have also identified pathway and system enhancement requirements that will support further application of this approach within home care delivery generally. The same findings are being replicated in the remaining four sites as they progress to completion.

A framework of implementation that supports area-led implementation of personalised supports as a response to home care needs creates an opportunity for standardisation of approach to home care that can also incorporate local contextual difference. The proposed next phase of engagement as described above focuses on incremental implementation into a live system beginning to scale this approach to care delivery across several primary care networks. Incorporated within this proposed second phase programme is the development of a template for independent application by each area that can support a final scaling of approach across each CHO area.

9.0 References

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Community Supports Model
www.genio.ie/community-supports-model [last accessed 9th October 2018]

HSE & Genio Dementia Programme www.genio.ie/dementia-programme [last accessed 9th October 2018]

Economic Analysis
www.genio.ie/economic-analysis-dementia [last accessed 9th October 2018]

Appendices

Appendix 1

Local Health Office Area	Acute Hospital	Community Healthcare Organisation (CHO)
Dublin North	Beaumont Hospital	CHO area 9
Dublin North Central	Mater Hospital	CHO area 9
Dublin West	Tallaght Hospital	CHO area 7
Dublin South East	St. Vincent's Hospital	CHO area 6
Waterford	University Hospital Waterford	CHO area 5
Cork City	Cork University Hospital	CHO area 4
Limerick	Limerick University Hospital	CHO area 3
Galway	Galway University Hospital	CHO area 2

CHO AREAS ACROSS IRELAND

Report 3: Recommendations

Personalised supports for people with dementia

Personalised supports for people with dementia provide a bespoke response that meets the individual needs of the person with dementia. As reflected by Tom Kitwood, a person's experience with dementia will be influenced by their physical and cognitive need, their personality and life history and social psychology that surrounds them. How these elements are supported will impact the quality of life that a person with dementia may have.

The following five principles underpin a personalised approach and inform how the person with dementia will be supported across the spectrum of health and social needs.

1. **The person with dementia and their primary carer are central to designing 'what they need'.**
    The person, their primary carer and the practitioner work collaboratively to identify health and social care need and create an individual plan of support. No pre-determined list of services is presented, rather discussion takes place about how life is currently, what challenges are experienced, or concerns exist, with consideration given to how those challenges or concerns can be addressed. The needs of both the person with dementia and their primary carer are considered.

2. **The supports are flexible and responsive to the stage of illness and the co-morbidities that exist.**
    Personalised supports are flexible and responsive to the changes that occur as dementia progresses. Increases may be required at times of crisis such as primary carer illness or as the person's needs increase. No pre-determined hours are prescribed, rather supports are provided at a time and in a way that meets individual need. Supports are reviewed to adjust to changing need on an ongoing basis.

3. **Adopt a normalising approach to dementia.**
    Personalised supports adopt a normalising approach to dementia by supporting maintenance of ability and connection to the relationships and social connections always enjoyed by the person. Support responses are provided in an individual way rather than being group based or segregating in approach.

4. **Maintain dignity, recognising the strengths, existing capacities and life history of the person, avoiding an exclusive focus on deficits.**
    The person with dementia is particularly vulnerable to premature loss of ability and connection. Change in these aspects can occur as a result of the condition itself, but also because of how supports might be delivered in a way that focuses on 'doing for' rather than 'doing with'. Supports that 'do with' the person will enable them to remain at their best level of ability at any given time.

5. **Build a support network using family and community supports, then mainstream services and finally formal health and social care supports to fill identified gaps.**
    No one service or organisation could or indeed should provide the full range of supports and services that people with dementia might require. Rather the natural circles of supports that exist for the person such as family, wider social networks, mainstream services and finally formal health and social care supports all have a very valuable role to play in supporting the person with dementia. All supporting partners and their potential contributions to supporting the person with dementia are considered and included where appropriate in the plan of care designed.

**Designing and implementing personalised supports with the person with dementia and their primary carer.**

The assessment of need for both health and social needs are ascertained by completing the CSAR and the following supporting documentation. Findings from both will then inform the schedule of services by reflecting the needs identified, and how they will be met.

1. **Discussion with the person with dementia and their primary carer as they identify their most pressing need. List the most pressing need.**

   _____

2. **Collaboratively identify with the person and their primary carer what their physical/ clinical needs are.**
   Please complete the CSAR and any required assessments to ascertain the physical/clinical needs of the person.

3. **Collaboratively map with the person and their primary carer their natural circles of support.** Based on the information gathered above and from the completion of the CSAR form, complete the following care and support network map – identifying who are the key people and services who can play an active role in supporting this person. This exercise will help inform how the person may best be supported and by whom within this network.
   (Sample framework attached Fig. 1. Blank template attached for completion with the person and their primary carer Fig. 2.)

CARE AND SUPPORT NETWORK Fig. 1
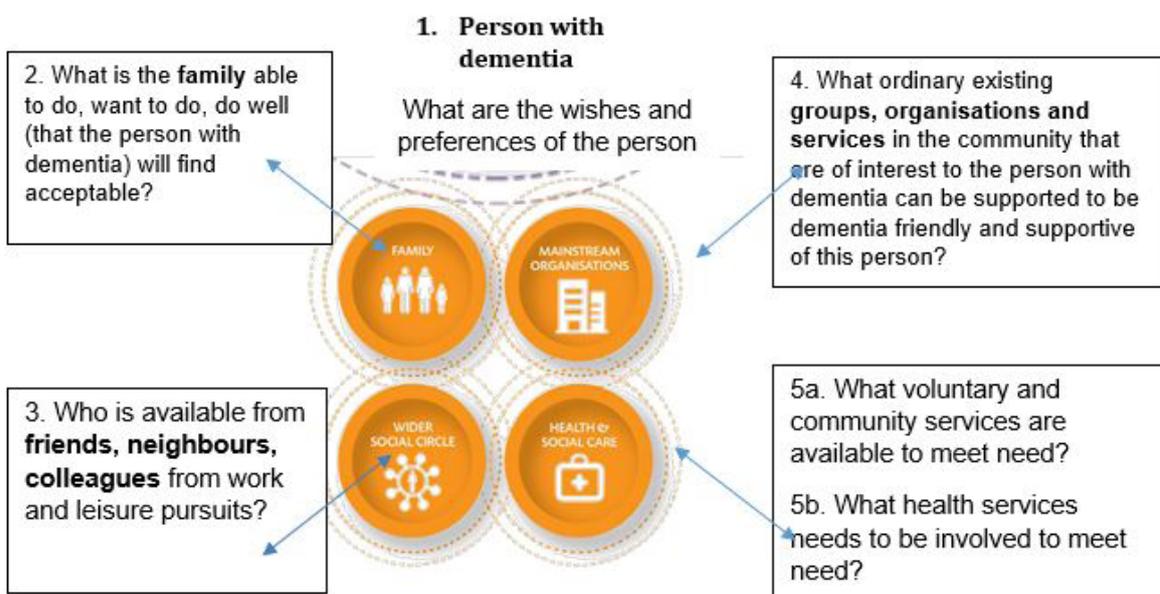
Supports are normalising and provided flexibly and reponsively

Care and Support Network Fig. 2

Family – Who in the family is important to the person and plays an active role in supporting the person?	**Mainstream Services** What existing groups and organisations or services does/has the person engaged with and could be supported to be dementia friendly and develop a supporting role. E.g. Shops, Leisure/Activity/Support Clubs, Post Office/Bank, Church.
Wider Social Network *e.g. who does the person consider their neighbours, friends, work and leisure colleagues who are/could be involved in supporting the person?*	**Social Care** What social care supports does/could the person engage with? *e.g. voluntary and community groups, meals on wheels, day care.*
Health Care What health care supports does the person have and what are the remaining gaps in support needs that exist for the person?	

4.   Collaboratively identify with the person and their primary carer if the current services in place require adjustment due to the person's changing needs or circumstances.

_____

_____

_____

SCHEDULE OF SERVICES - Based on the information collected above begin to complete the following schedule of services.

*Support Type: TD Timely diagnosis, PDS Post Diagnostic Support, MA Maintain Ability, MC Maintain Connection, RS Respite Support, AT Assistive Technology.

*Care and Support Network F: Family W: Wider Social Network M: Mainstream Services H: Health Services S: Social Care

*SUPPORT TYPE (TD, PDS, MA, MC, RS, AT)	NEEDS IDENTIFIED What are the person's support needs?	SUPPORT RESPONSE What is the care and support plan that will be implemented?	*Who from Care and Support network can meet these needs?						Frequency	Time
			F	W	M	H	S			
			F	W	M	H	S			
			F	W	M	H	S			
			F	W	M	H	S			
			F	W	M	H	S			
			F	W	M	H	S			

Total Hours of Support _____ No. of above hours already in place _____ No. of additional hours requested _____

Review Date: _____ Signed: _____

Original Dementia Specific Intensive Homecare Community Pathway – with proposed enhancements to process highlighted
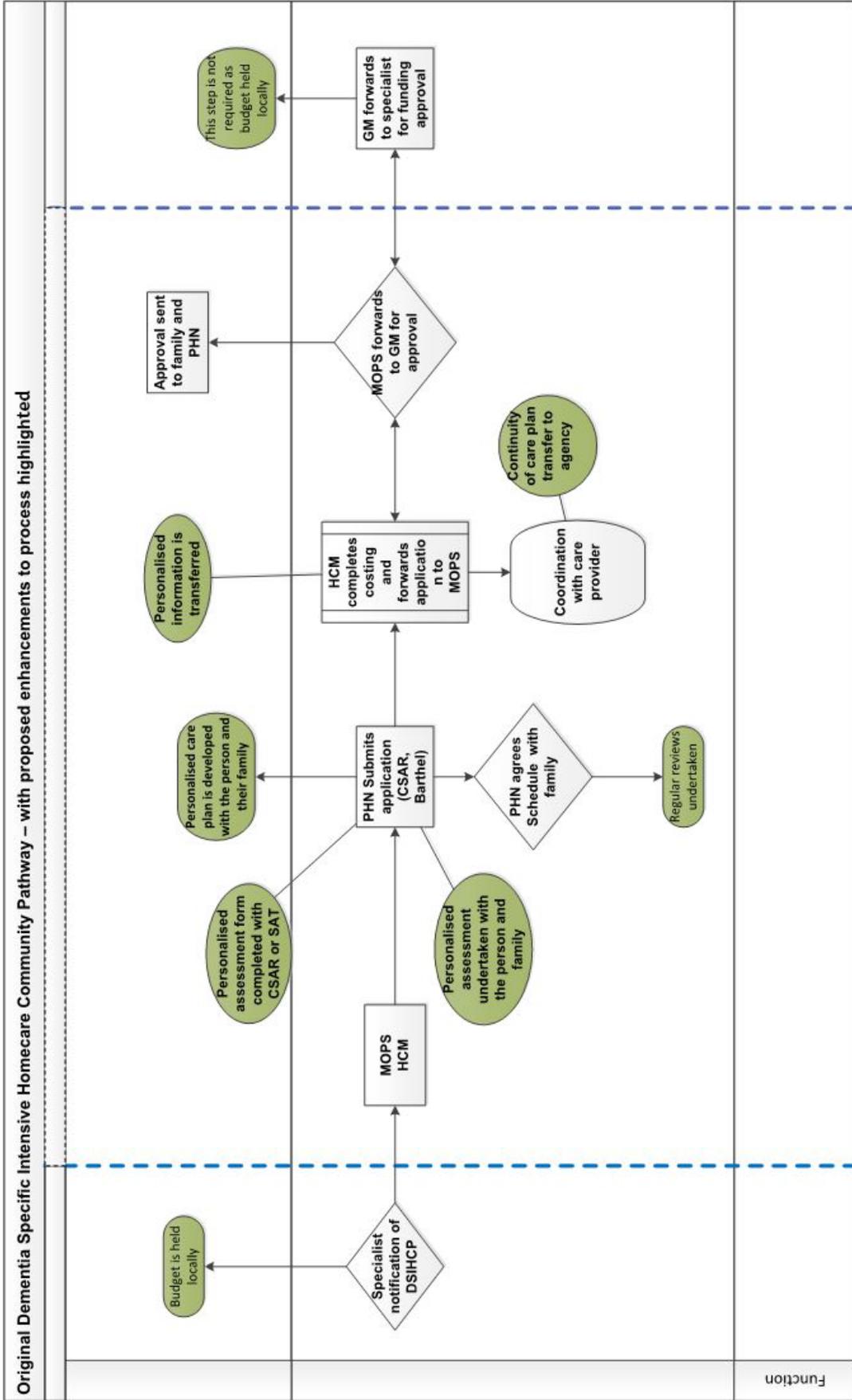
A copy of this report can be downloaded from www.genio.ie/dementia-report3-personalised