INDEPENDENT EVALUATION OF THE DEMENTIA WHOLE-SYSTEM CARE CO-ORDINATION PROGRAMME

Scottish Government – Final report

September 2022

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EXECUTIVE SUMMARY

Introduction

RSM UK Consulting LLP (RSM) was commissioned by the Scottish Government in February 2022 to undertake an independent evaluation of the effectiveness and impact of the programme in delivering a locality-based whole-systems approach to dementia care and services.[1]

To help meet key commitments of the Scottish Government's Third National Dementia Strategy (2017), the Dementia Care Co-ordination Programme was established and led by Healthcare Improvement Scotland (HIS). Inverclyde Health and Social Care Partnership (HSCP) was selected as the Dementia Care Co-ordination Programme implementation test site. Inverclyde HSCP was supported by Healthcare Improvement Scotland's (HIS) Focus on Dementia (FOD) team and Alzheimer Scotland from June 2019 to March 2022, to redesign their dementia pathways from diagnosis to end-of-life care, and to share learning across Scotland. The programme contains three main aspects, the aims of which are summarised in the table below:

Table 1: Three main aspects of the Dementia Care Co-ordination Programme in Inverclyde

Workstream	Aim of the workstream
Post diagnostic support (PDS)	To ensure the best possible support for people newly diagnosed with dementia, by meeting the standards expected of a quality PDS service as detailed in the Quality Improvement Framework.
Care co-ordination and the Alzheimer Scotland 8-pillar model of community support	To deliver a co-ordinated, integrated, timely service to support people with dementia, their families and carers. This also includes undertaking effective risk management, reducing crisis situations and reducing hospital admissions where possible.
Alzheimer Scotland Advanced Dementia Practice Model (ADPM)	To test this model within Inverclyde and ensure people with dementia are able to access palliative and end of life care, delivered by the right professional and service at the right time, as per other terminal conditions.

Story of the Programme

The Dementia Care Co-ordination Programme was commissioned by Scottish Government Ministers in 2018 to HIS to help meet key commitments of the Scottish Government's Third National Dementia Strategy (2017). Inverclyde was chosen from eight applicants, following a competitive application process as a test site for local implementation of national policies.

The Programme began in June 2019, however due to pressures on frontline services arising from the Covid-19 pandemic, was paused twice[2], and the Scottish Government agreed to fund the Programme for an additional year until March 2022. Total programme funding was £411,713 from the Scottish Government of which £190,318 was to Focus on Dementia Healthcare Improvement Scotland. The funding related to the following two posts; NHS Greater Glasgow & Clyde Health Board Improvement Advisor and Alzheimer Scotland Public Policy Consultant. Also a Senior Improvement Advisor (quality improvement), data, measurement, evaluation and project management support were provided by Healthcare Improvement Scotland.

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[1] The RSM team worked in conjunction with an academic advisor, Dr Barbara Sharp, who provided subject matter expertise and provided review and commentary on our draft findings and report.

2 These Programme pauses consisted of one complete pause and one reduced service pause.

To deliver these three workstreams, both a Programme Steering Group and Operational Group were established along with several working groups/ forums (eg. the Advanced Dementia Model Practice Group and Advanced Dementia Specialist Forum) and sub-groups (eg. the App Development Group and Data Sub-Group). A number of outputs were produced throughout the Programme, including the Inverclyde Dementia and Support Services Leaflet, Learning Disabilities Advanced Dementia and Care Home Needs Guidance Note and, ongoing development of the Living well with Dementia app.[3] The outputs of the Programme are intended to benefit those living with Dementia and their carers within the Inverclyde locality and support learnings for wider implementation across Scotland. In 2020/ 2021 there were an estimated 831 people being treated for Dementia living within Inverclyde. However, this is challenging to quantify due to disruptions to diagnostic processes during the Covid-19 pandemic.

Methodology

A mixed-methods approach has been adopted for this evaluation, combining both qualitative and quantitative research approaches. The methodology for this report included:

Quantitative research: Secondary analysis of existing data and programme information has been used to gather evidence against the intended outcomes of the programme.

Qualitative research: Qualitative evidence was gathered via the research tools below.

- **Desktop review:** From the documents received, we have undertaken a review to build the story of the programme. Using the evaluation framework in Annex 9, we have considered evidence related to the activities of the programme, the outputs, and outcomes.
- **Interviews with strategic stakeholders:** **Seven** virtual interviews have taken place.
- **Reflective focus groups with key stakeholder groups:** **Eight** reflective online focus groups were held with operational delivery groups (x3), specialist and lived experience groups (x3) and steering group members (x2).
- **Follow up interviews:** **Five** deep-dive interviews were undertaken to deep dive into specific thematic areas.
- **Social listening and observation at programme events:** **Three** events were attended to understand ongoing communications around the programme**.**

Limitations of the evaluation: challenges associated with a summative evaluation (eg. some of the staff involved in the programme being no longer in post) and gaining the involvement of those living with dementia and their carers due to the ongoing impacts of the Covid-19 pandemic.

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[3] Further outputs are discussed in the Story of the Programme chapter.

Key findings

Outcomes and impact of the programme

Outcome 1: A personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer

- Interviews and focus groups suggested that early intervention was key to avoiding individuals having to go into residential care earlier than expected.
- Carers (n=2) and staff referenced the leaflet and Access First telephone line as useful tools to signpost individuals to services and live independently.
- Greater links to the third sector have created greater opportunities for support within the community for people living with dementia.
- Stakeholders anticipated that the app would allow individuals to better manage their own wellbeing (once live).

Outcome 2: A better person experience, improved quality and better outcomes for people in the area living with dementia and their families/ carers

- Joined up care has been key in providing a quality service for those living with dementia – facilitated by regular communication between system partners including regular meetings and progress reports
- The ongoing collaborative work of the Dementia Reference Group was vital in ensuring that the views of those with lived experience and their families/carers were incorporated into the Programme.
- The Advanced Dementia Specialist Forum was helpful in increasing staff knowledge of available resources and interventions and, as a result providing support to individuals to stay at home for longer.
- Staff now have a greater awareness of the services available to those living with dementia and their families/carers and can refer to these services at an earlier stage, which led to positive outcomes.
- Increased PDS link worker resource has contributed to reduced PDS waiting lists meaning individuals are being referred and receiving care during early dementia.
- Impact may have been greater in the absence of Covid-19.
- To explore the extent to which this outcome has been fully achieved, further data collection and analysis (particularly of outcome data) will be required over a longer period of time. Additional consultation of those with lived experience and their families/ carers would also be beneficial.

Outcome 3: A more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care

- Strong existing culture of integration within Inverclyde and an evident willingness from all system partners to work together, particularly with the third sector (for example, housing associations, charities and community organisations).
- Strong and visible leadership within Inverclyde was positive for collaboration. In particular, the introduction of an improvement advisor for the programme, working within Inverclyde HSCP, was referenced as being a key enabler.

- Collaborative learning opportunities (such as learning sessions & associated flash reports) ensured all partners are more aware of services on offer within the local region and have a good understanding of each partners' roles and responsibilities.
- Carers suggested that it was too early to determine if care was more integrated.
- High levels of collaboration were particularly positive given the context of Covid-19.

Outcome 4: Effective monitoring and measurement approaches that can adequately assess the effectiveness and quality of the 'whole system' locality approach

- Throughout the programme, there has been evidence of ongoing feedback and monitoring, provided by Scottish Government and HIS.
- A key outcome of the programme was developing the Dementia Measurement & Performance Framework and the collation and analysis of data (eg. dementia prevalence and PDS activity) in a systematic manner. At the point of the evaluation, a range of data metrics have been collated, with work around the dementia register is ongoing.
- Flash reports (including learning session and steering group reports) were helpful for staff members in monitoring achievements as the programme progressed.
- Covid-19 had an impact on data analysis and activity trends related to this (eg. changes to service delivery during the pandemic has influenced the levels of service activity).
- Going forward, some focus group participants suggested there should be a renewed focus on accessing and monitoring trends in third sector data
- Focus group participants also mentioned the potential use of dementia prescriptions to monitor services and trends over time (participants did not make the distinction between pharmacological prescriptions and social prescriptions for non-pharmacological interventions).

In addition to three thematic case studies (relating to the development of the Living Well with Dementia App, the role of AHPs in the programme and sustainability), a number of wider thematic areas of interest were observed during the evaluation. These included: an existing culture of collaboration (which was further embodied through useful regular meetings and case reviews); a committed and passionate approach amongst staff and stakeholders (including HIS, Scottish Government, Inverclyde Health and Social Care Partnership and third sector partners) to getting the Programme up and running again with a renewed focus following Covid-19 related pauses; innovative use of digital solutions; strong leadership at all levels. Whilst there was some uncertainty about the implications that the programme might have on the development of the National Care Service, it was felt that many key principles were in place via the programme which would enhance this service.

Key conclusions and areas for consideration

Has the programme delivered on its aims and objectives?

To meet the aims and objectives of the programme, a number of key deliverables have been developed throughout the programme, including the Inverclyde Dementia and Support Services Leaflet, care co-ordination delivery and care co-ordinator role document, Learning Disabilities Advanced Dementia and Care Homes Needs Guidance, AHP, Housing and Dementia Framework, frailty work and Living Well with Dementia App (currently being tested).[4] A number of internal evaluations have also been undertaken to test a range of outputs and elements of the

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[4] The programme also fed into other programmes of work being undertaken.

model of Care Co-ordination, such as the PDS Weekly Meetings and the ADSF. It was identified that the ongoing work of the Dementia Reference Group was vital in ensuring that the views of those with lived experience and their families/ carers were incorporated into the Programme.

Learnings were shared using the flash reports (including learning sessions and steering group reports), PDS Lead meetings, Delivery Group meetings, Focus on Dementia Learning Systems and at an Alzheimer Scotland event on 5th September 2022. However, there was some suggestion that learning was shared to a lesser extent with NHS Greater Glasgow and Clyde (NHSGGC) and nationally than otherwise would have, due to the Covid-19 pandemic.

Has the Programme delivered its intended outcomes?

The Programme has four overarching outcomes. A summary of whether each outcome was achieved has been included below:

Outcome 1: A personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer.	**Achieved:** Early intervention was regarded as key to avoiding individuals having to go into residential care earlier than expected. Greater links with the third sector (for example, housing associations, charities and community organisations), joined up working between HSCP services and tangible resources (such as the leaflet and the Access First telephone line) were considered important in enabling people to self-manage and live independently for longer.
Outcome 2: A better person experience, improved quality and better outcomes for people in the area living with dementia and their carers.	**Partially achieved**:Joined up care has been key in providing a quality service for those living with dementia, which has been facilitated by regular communication between system partners. A future programme evaluation will be able to determine if longer-term outcomes have been fully achieved (particularly when further evidence from people living with dementia and/or their carers is available, which proved to be a limitation within this evaluation).
Outcome 3: A more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care.	**Partially achieved: -** There has been a strong existing culture of integration within Inverclyde, which has been supported by an evident willingness from all system partners to work together, particularly with the third sector. A future programme evaluation will be able to determine if longer-term outcomes have been fully achieved, particularly when further evidence from people living with dementia and/or their carers is available, which proved to be a limitation within this evaluation.
Outcome 4: Effective monitoring and measurement approaches that can adequately assess the effectiveness and quality of the 'whole system' locality approach.	**Partially achieved:**Throughout the programme, there has been evidence of ongoing monitoring and measurement processes. However, Covid-19 had an impact on data analysis and activity trends related to services and there has been limited collection of longer-term outcome measures to be able to understand how the Programme has changed the outcomes of those with dementia. Further work which is ongoing on data collation (including any aspects which could be taken forward nationally) should support the achievement of this objective in the medium to longer term.

Has the Programme delivered on Government policy?

To help meet key commitments of the Scottish Government's Third National Dementia Strategy (2017), the Dementia Care Co-ordination Programme was established, with Inverclyde selected as the implementation site. It has been found that the Inverclyde Dementia Care Co-ordination Programme builds upon previous policy, including the National Dementia Strategy (2010)[5], the National Dementia Strategy (2013),[6] Charter of Rights[7] and PANEL principles[8]. The Programme's workstreams and activities undertaken have been deemed to have helped deliver these policies in a real and meaningful way.

Key local factors from the Inverclyde system that could be replicated elsewhere in Scotland

The importance of having a dedicated project improvement advisor: This role was highlighted as having a clear link to the success of the Programme and providing central steering and consistency. In addition, the appointment of the dementia training co-ordinator was regarded as a positive output from the Programme.

Development of close links with the third sector and HSCP services: Going forward, other systems should consider a stakeholder mapping exercise, to chart all partners in their localities (eg. housing associations, charities and community organisations), highlight barriers to access and how those barriers can be overcome. Consider organising an introductory meeting (with thematic breakout rooms) to further these connections, with periodic meetings to provide updates and ensure sustainability. Creating an internal contact directory would also be beneficial, as it would outline each partner's role and contact details, facilitating communication.

Hosting regular programme meetings, accompanied by briefs and action logs: Going forward, given the range of stakeholders likely to be inputting into such a programme, this systematic meeting approach should be adopted by other systems.

General programme structure: The general structure of the programme as a whole may serve as a blueprint to support an improvement agenda in other localities (eg. the establishment of a Steering Group, Dementia Reference Group and App Development Group etc). The effectiveness of these groups was not evaluated due to the summative nature of this evaluation; however, stakeholders reinforced that effective leadership at all levels (including leadership of these groups) was key to the success observed within Inverclyde.

Consider how learnings from Inverclyde can be shared nationally: Outputs of the programme that are well-received by those living with dementia and their families/ carers (such

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[5] Scottish Government (2010) *Scotland's National Dementia Strategy:* Scotland's National Dementia Strategy (wdhscp.org.uk)

[6] Scottish Government (2013) *Scotland's National Dementia Strategy (2013-2016):* Scotland's National Dementia Strategy (https://www.webarchive.org.uk/wayback/archive/3000/https://www.gov.scot/Resource/0042/00423472.pdf)

[7] Alzheimer Scotland (2009) *Charter of rights for people with Dementia and their carers' in Scotland:* Charter of Rights for People with Dementia and their Carers in Scotland (alzscot.org)

[8] Scottish Human Rights Commission, *A Human Rights Based Approach: An Introduction:* shrc_hrba_leaflet.pdf (scottishhumanrights.com)

as the leaflet and access first telephone line) could be shared with other areas to adapt for their own programmes. National networks for localities with dementia programmes should be used throughout Scotland, to collaborate and share good practice where possible. Where these groups do not already exist, there may be merit in developing a network.

Key factors for other systems and the Scottish Government to consider when developing a similar programme

Based on quantitative analysis conducted the development of a Theory of Change model, which is updated on a quarterly basis to reflect programme developments: Having linkages within the model to specific diagnosis metrics is also important for improving data collation. It is important to ensure that there is sustained resource capacity for data collection and analysis, to support this ongoing work.

Develop an outcomes framework to measure the impact of services on people with dementia and their families nationally: This will support local systems to monitor and evidence the impact (short, medium and long-term) of their dementia service offer on a consistent basis with other local systems in Scotland.

Create a robust data collection system and ensure there is sufficient dedicated resource to monitor data: The ability to use data in a systematic manner will enable programmes to evidence change, allowing for the ongoing assessment of progress.

Consider incorporating formative evaluation activities into the programme from the inception: This will allow the programme to track progress over time and will capture ongoing insights from all staff (key in the event of staff moving posts).

Including direct involvement of those with dementia and their families/ carers within a programme: Having the knowledge and input of those with lived experience is key in ensuring that any programme outputs are relevant, useful and accessible. It is important to ensure that this includes people living with different types of dementia, from a range of age groups and with different levels of advancement, to collect a broad range of experiences.

ACRONYMS

Acronym	Description
ADSF	Advanced Dementia Specialist Forum
ADPM	Alzheimer Scotland Advanced Dementia Practice Model
COSLA	Convention Of Scottish Local Authorities
FOD	Focus on Dementia
HIS	Healthcare Improvement Scotland
HSCP	Health and Social Care Partnership
NCS	National Care Service
NHSGGC	NHS Greater Glasgow and Clyde
PDS	Post Diagnostic Support
RSM	RSM UK Consulting LLP
SIMD	Scottish Index of Multiple Deprivation
WHO	World Health Organisation

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FOREWORD

I am delighted to have worked in partnership with RSM UK to undertake this evaluation of the Dementia Care Co-ordination Programme in Inverclyde HSCP, on behalf of the Scottish Government. I would like to extend my thanks to the Project Team for their thoughtful comments on research tools and reports, and for their ongoing participation in the evaluation. I am also grateful for their efforts in linking the evaluation team with staff and people whose lives are affected by dementia, ensuring that their views have been included in this evaluation. It is evident that significant time, effort, skill and commitment has gone into setting-up and implementing the Dementia Care Co-ordination Programme within Inverclyde. The Programme has been driven and delivered by a passionate team of dedicated staff, with valued support from Alzheimer Scotland, Healthcare Improvement Scotland and the Scottish Government. Also commendation should be given to the Dementia Reference Group, which made sure that there was representation from those with lived experience.

Despite the Covid-19 pandemic, which led to delivery pauses and an unprecedented demand on health and social care and voluntary services, the Programme has delivered a number of key outputs. These include the development of the Inverclyde Dementia and Support Services Leaflet for those with Dementia and their families/ carers, testing of a single quality question, continuing development of the Living Well with Dementia App, piloting of the Advanced Dementia Specialist Forum, and an evaluation report for the Advanced Dementia Specialist Model/ Forum. But most of all, the team have been committed to creating a culture of service and quality improvement during the most difficult of times and have received praise from those who benefitted from their support.

The Programme team have shown resilience in the face of the Covid-19 pandemic and have remained committed to the underpinning philosophy of integrating the views of those with lived experience and their families/ carers into the Programme, particularly through the Dementia Reference Group. Despite challenges relating to face-to-face interaction during the pandemic, engagement continued where possible, illustrating a commitment to delivering quality care. The team also remained committed to the development of a dataset which includes all known people with a diagnosis of dementia within the Inverclyde locality.

The Programme should serve as a good practice example for Dementia Care Co-ordination nationally in Scotland but might also be seen as a beacon of good practice throughout the UK and potentially also internationally. There have been some key learnings, not just to guide potential future implementation of this (or other) Programme(s) in Scotland, but also that could guide other health and social care systems more widely. In addition, the way in which national policy has been implemented and delivered locally is an important lesson for the National Care Service.

Moving forward, the work of the Programme should be sustained and embedded into service delivery, supported by further data collation and evaluation particularly targeted at quantifying longer term outcomes and impacts on people living with dementia, their families, and carers.

Dr Barbara Sharp

1. INTRODUCTION

1.1.1 Background and context

The Dementia Care Co-ordination Programme was commissioned by Scottish Government Ministers to Healthcare Improvement Scotland in 2018 to help meet key commitments of the Scottish Government's Third National Dementia Strategy (2017)[9]. This strategy highlights the shared vision of *"a Scotland where people with Dementia and those who care for them have access to timely, skilled and well co-ordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them"*. HIS undertook a selection process in collaboration with other national partners, including Scottish Government, and people with dementia and carers. Inverclyde Health and Social Care Partnership (HSCP) was selected as the Dementia Care Co-ordination Programme implementation site. The Programme is supporting improvements to, and the redesign of, community-based services with the aim of improving care co-ordination for people with living with dementia, from diagnosis to end of life.

Inverclyde HSCP was supported by Healthcare Improvement Scotland's Focus on Dementia team and Alzheimer Scotland from June 2019 to March 2022 to redesign their dementia pathways from diagnosis to end-of-life care, and to share learning across Scotland. In Scotland, those with a dementia diagnosis have the right to a minimum of a year of post diagnostic support (PDS). In Inverclyde, this is co-ordinated by an Alzheimer Scotland PDS link worker, often called a Dementia link worker, who is allocated to each individual for at least one year.[10] Normally after the initial period of PDS, those living with dementia and their families/ carers should have a personal care plan developed to co-ordinate care and support going forward. However, without continuity or co-ordination, people with dementia and their families/ carers may experience fragmented care from a number of providers, which often results in duplication of effort and preventable hospital admissions. This Programme therefore aimed to address these challenges by developing and embedding an integrated, whole system approach to the delivery of support from diagnosis to end of life. The learning from this work will inform the scale up and spread of this work to other areas in Scotland.

The Programme aimed to achieve this quality improvement and redesign approach by supporting the implementation of the following frameworks: :

- the 5 Pillar Model of PDS;
- the 8 Pillar Model of Community Support (to support people with dementia living at home during moderate to severe symptoms of the condition); and
- testing the Advanced Dementia Practice Model (for those with the most complex health care needs).

Care Co-ordination is defined by the World Health Organisation (WHO)[11] as *"a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings"*. Co-ordinating care for those with dementia provides a range of benefits for the person, their carers

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[9] Scottish Government *National dementia strategy: 2017-2020*

[10] Not all areas in Scotland use Alzheimer Scotland to provide PDS - for example some link workers operate within community mental health teams, and PDS is often delivered by a CPN or other staff members from a HSCP.

[11] World Health Organisation (2018) *Continuity and Coordination of care*

and the wider health and social care system. The benefits associated with care co-ordination, as detailed by Healthcare Improvement Scotland, are summarised below:

Figure 1: Benefits of care co-ordination

Makes access to a range of health, social and welfare services easier

Case management and high continuity can lead to a reduction in hospital admissions

One study found co-ordination led to a 27% reduction in emergency visits

Case management can help those with dementia to re-engage socially

One study found that 63% patients value seeing someone they trust on a continual basis

Case management and outcome based care can reduce caregiver burden and improve their quality of life/ wellbeing

Case management offsets the cost of increased use of community services leading to overall cost savings

Provides reassurance that support can be available as and when needed which is valued by those with dementia and their carers

Source: Healthcare Improvement Scotland[12]

1.1.2 Objectives of the programme

The overall objective of the Dementia Whole-System Care Co-ordination Programme was to develop and embed an integrated, whole system approach to the delivery of support from diagnosis to end of life.

The Inverclyde Dementia Care Co-ordination Programme aimed to improve the experience, safety and co-ordination of care, services and support for people living with dementia and their carers. The emphasis was on supporting people to stay well at home or in a homely setting for as long as possible. These overarching outcomes included:

- **Outcome 1:** A personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer.
- **Outcome 2:** A better person experience, improved quality, and better outcomes for people in the area living with dementia and their carers.
- **Outcome 3:** A more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care.
- **Outcome 4:** Effective monitoring and measurement approaches that can adequately assess the effectiveness and quality of the 'whole system' locality approach.

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[12] Healthcare Improvement Scotland (2020) *Key benefits of dementia care co-ordination*

The Programme had a number of aims including:

- Developing and evaluating a model of effective care co-ordination for people with dementia and their carers from diagnosis to end of life;
- Improving care co-ordination for people with dementia and their carers; and
- Sharing learning across NHS Greater Glasgow and Clyde (NHSGGC), Scotland and further afield.

The Programme built on previous work on care co-ordination in Scotland, including:

- Further testing of Alzheimer Scotland's 8 Pillar Model of care co-ordination (2013)[13];
- Evaluation of Midlothian's model of care co-ordination (2019)[14]; and
- The identification of 12 critical success factors that support effective care co-ordination, by the Midlothian Health and Social Care Partnership (HSCP) (2020)[15].

1.2 Aims of the evaluation

The primary purpose of this evaluation is to determine the impact and effectiveness of the Dementia Whole-System Care Coordination Programme in delivering a locality-based whole-systems approach to dementia care and services. This evaluation aims to understand the integration of dementia services and support within the Inverclyde locality, and what this feels like for people with dementia and their families. It describes the story of the Programme and how it has evolved over time and also **the extent to which planned outcomes have been achieved, linked to the Theory of Change** which identifies inputs, activities, outcomes, impact, and outputs of the Programme**.** In doing so, the evaluation also captures learning on what worked well, why, where and to what cost. There has been a focus on the **enablers and barriers for delivery and implementation** and **specific learnings related to a number of thematic areas** across the following areas:

- Critical success factors for Inverclyde across the three aspects of dementia support – PDS, care coordination and advanced dementia practice model;
- Learning from Covid-19 and new ways of working;
- Learning related to the use of digital solutions;
- The role of national and local systems in their facilitation of the Programme; and implications for learning related to a future landscape that could involve the National Care Service. [16]

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[13] Alzheimer Scotland (2013) *Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support. An independent evaluation of this model was conducted in 2016* evaluation-effectiveness-8-pillars.pdf (ihub.scot)

[14] Healthcare Improvement Scotland, Alzheimer Scotland and Midlothian Health and Social Care Partnership (2020) *Care co-ordination in the community for people with dementia in Midlothian*

[15] Healthcare Improvement Scotland (2020) *Care co-ordination in the community for people with dementia in Midlothian: Summary of an appreciative inquiry and data analysis to understand the critical success factors*

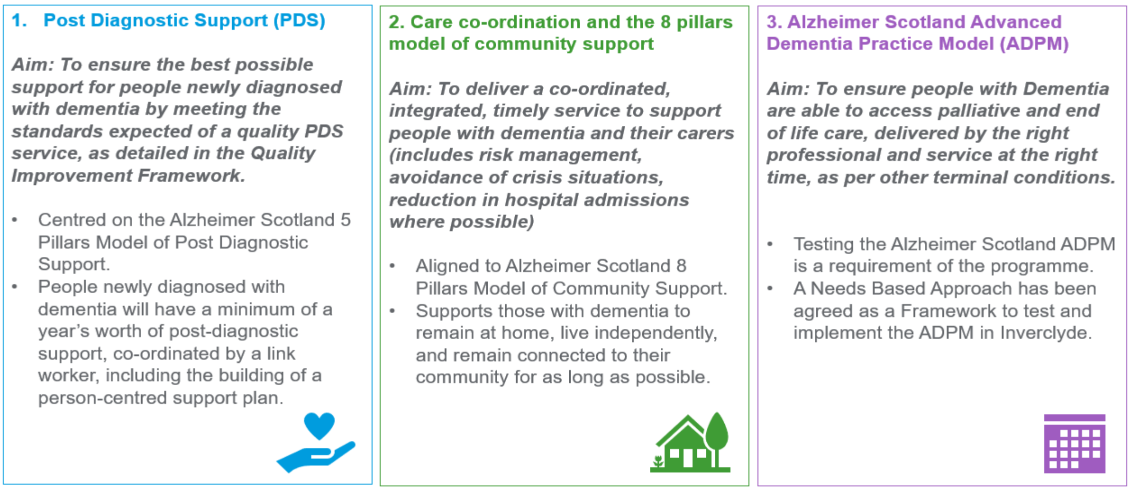
[16] HIS Care Co-ordination in the community for people with dementia in Midlothian (2020) (https://ihub.scot/media/7397/20200930-his-as-midlothian-report-v10.pdf)

2. STORY OF THE PROGRAMME

2.1.1 Programme background

The Inverclyde Dementia Care Co-ordination Programme began in June 2019 as a test site for local implementation of key commitments of Scotland's dementia strategies. However during the first wave of the Covid-19 pandemic, the Programme was paused for six months to ensure no additional pressure on frontline services. The programme recommenced in September 2020, and to mitigate impact from the pandemic, the Scottish Government agreed to fund the Programme for an additional year until March 2022. The Programme was again paused between January 2021 – February 2021 to reduce pressure on clinical staff (however limited activities were able to run in the background). Following recommencement, the Programme's priorities and action plan were reviewed, taking account of what was likely to be achievable from February 2021 to March 2022. The three main approaches are summarised in the diagram below:

Figure 2: Three main approaches of the care co-ordination programme



1. Post Diagnostic Support (PDS)

Aim: To ensure the best possible support for people newly diagnosed with dementia by meeting the standards expected of a quality PDS service, as detailed in the Quality Improvement Framework.

- Centred on the Alzheimer Scotland 5 Pillars Model of Post Diagnostic Support.
- People newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support, co-ordinated by a link worker, including the building of a person-centred support plan.

2. Care co-ordination and the 8 pillars model of community support

Aim: To deliver a co-ordinated, integrated, timely service to support people with dementia and their carers (includes risk management, avoidance of crisis situations, reduction in hospital admissions where possible)

- Aligned to Alzheimer Scotland 8 Pillars Model of Community Support.
- Supports those with dementia to remain at home, live independently, and remain connected to their community for as long as possible.

3. Alzheimer Scotland Advanced Dementia Practice Model (ADPM)

Aim: To ensure people with Dementia are able to access palliative and end of life care, delivered by the right professional and service at the right time, as per other terminal conditions.

- Testing the Alzheimer Scotland ADPM is a requirement of the programme.
- A Needs Based Approach has been agreed as a Framework to test and implement the ADPM in Inverclyde.

2.1.2 Strategic alignment to national policies

The Programme built on earlier work on dementia that was taking place nationally, including the National Dementia Strategy (2010)[17], National Dementia Strategy (2013)[18], Charter of Rights[19] and PANEL principles[20] that were previously adopted. The table below displays several key national strategic documents and highlights the alignment between the Programme workstreams and activities undertaken, and how they contribute to the wider national landscape in a real and meaningful way.

Figure 3: Strategic alignment of programme with national priorities

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[17] Scottish Government (2010) *Scotland's National Dementia Strategy:* Scotland's National Dementia Strategy (wdhscp.org.uk)

[18] 18 Scottish Government (2013) *Scotland's National Dementia Strategy:* Scotland's National Dementia Strategy (2013-2016)

[19] Alzheimer Scotland (2009) *Charter of rights for people with Dementia and their carers' in Scotland:* Charter of Rights for People with Dementia and their Carers in Scotland (alzscot.org)

[20] Scottish Human Rights Commission, *A Human Rights Based Approach: An Introduction:* shrc_hrba_leaflet.pdf (scottishhumanrights.com)

Key documents	Programme workstreams and alignment to national strategic priorities			Programme level summary
	Post diagnostic support (PDS)	Care co-ordination and the Alzheimer Scotland 8-pillar model of community support	Alzheimer Scotland Advanced Dementia Practice Model (ADPM)	
Scottish Government (2017) National dementia strategy: 2017-2020 The strategy sets out the vision for improving access to support services, timely access to palliative care, person- centred care and raising awareness of dementia.	• The Dementia reference group was vital in ensuring that the views of those with lived experience was incorporated into the programme. • Early intervention allows mitigations to begin earlier and improve people living with dementias quality of life. • Single Quality Question allows people to provide feedback on the impact of PDS support.	• The 8-pillar model assists in providing joined up care for those living with dementia and providing quality care and access to support services when needed. • Learning sessions raised awareness of dementia for involved partners such as Police.	• Increasing staff knowledge of available resources and interventions available.	All programme activities have aligned with what has been set out in the National dementia strategy by providing personalised care and a bespoke approach to dementia care provision in Inverclyde.
Scottish Government (2016) Integration of Health and Social Care and Primary Care Transformation Plan Delivered through Integration Authorities to deliver well-coordinated care that is timely and appropriate to people's needs.	• Dementia support services leaflet was developed to provide information for support services for people living with dementia and has been used by clinicians. Link workers were regarded as key in providing tailored care as well as being a point of contact.	• Collaborative working between HSCP services were considered important in helping people to self-manage and live independently for longer.	-	The programme made positive steps in joining up services across Inverclyde, with system partners including the third sector working collaboratively and communicating regularly.
Scottish Government (2016) Carers Act 2016 The Act aims to ensure that people who provide unpaid care are supported to look after their health and wellbeing.	-	• Carers and family members now have a greater awareness of services available for those living with dementia. For example, LS5 enabled local service providers to better meet the needs of families and carers.	-	The activities of the programme contributed to ensuring carers have a greater awareness of the services and support available. However, carers felt that it was too early to assess the impact of the programme and whether care was more integrated.
Scottish Government (2015) Strategic Framework for Action on Palliative and End of Life Care 2016-2021 This framework sets out the key actions to allow everyone in Scotland to receive services that respond to their individual palliative and end of life care needs.	Enables people to plan for the future, through both the Living Well with Dementia app and PDS support.	• Continuity in care co-ordination delivery helps as people advance through their dementia journey.	• Dementia and Palliative Care Identification Tools Guide. • ADSF allows those with advanced dementia requiring palliative care needs to be met.	The ADPM model makes good attempts to adhere to the standards set out in the Framework, by providing people living with dementia, families and carers with guidance and advice on planning for late-stage dementia and end of life care.
Scottish Government (2017) Health and Social Care Standards: my support, my life The standards set out what people should expect when using health, social care and social work services in Scotland.	• PDS support enables people to make informed decisions about the care and support they want to receive. Enabling those living with dementia to be fully involved in decisions about their care. • Adoption of Single Quality Question to access feedback from support provided.	• Consistent support through living with dementia allows those living with dementia to have confidence in those supporting and delivering their care.	• ADSF gives the support needed to those with dementia to be treated with respect and dignity.	All activities undertaken in the programme have gone some way in contributing to the standards set out. Through improving dementia care, flexibility in approach to peoples care and to encouraging innovation such as through the development of the Living well with dementia app.
Scottish Government (2020) Coronavirus (COVID-19) - dementia and COVID-19: action plan Highlights how the Scottish Government intends to support people with dementia as we recover from COVID-19.	• PDS support contributes to a national commitment, to aid the COVID-19 recovery. • PDS support has increased access to services locally through a joined-up approach with partners and innovative activities such as the Living well with dementia app.	• Collaborative working between partners has further aided the integration of services in Inverclyde.	-	The programme's PDS support aligns with the actions plan's commitment 4 and 5 in delivering PDS support to increase access to services and community support.
Scottish Government (2011) Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy These standards lay out people living with dementia's rights in relation to care, treatment, and the support they need.	• PDS support enables people to live in the community for as long as possible.	• Personalised care planning enables people living with dementia to be treated as a unique individual. • Learning sessions delivered as part of the programme empower partners, families, and carers to have more information and awareness of dementia.	• The Palliative end of life tools guide allows people living with dementia to receive the end-of-life care that they want in a personalised manner.	All programme workstreams contribute to the standards of dementia care in Scotland.
Scottish Government (2016) Health and Social Care Delivery Plan Plan sets out Scottish Government's vision for health and care services so that people in Scotland can live longer, healthier lives at home.	• PDS workers provided personalised care and support. Creation of Support and services leaflet to promote people to self-manage and stay connected to their local community. • Early intervention regarded as key in avoiding individuals having to go into residential care earlier than expected.	• Initial support from PDS workers enables people to live more independently at home. PDS waiting lists also reduced at start of programme. • Increased care standards from upskilling staff through learning sessions.	-	Activities undertaken have gone some way in embedding an integrated, whole system approach to dementia. PDS support enables people living with dementia to experience a greater quality of life, living well at home and in their community for longer.

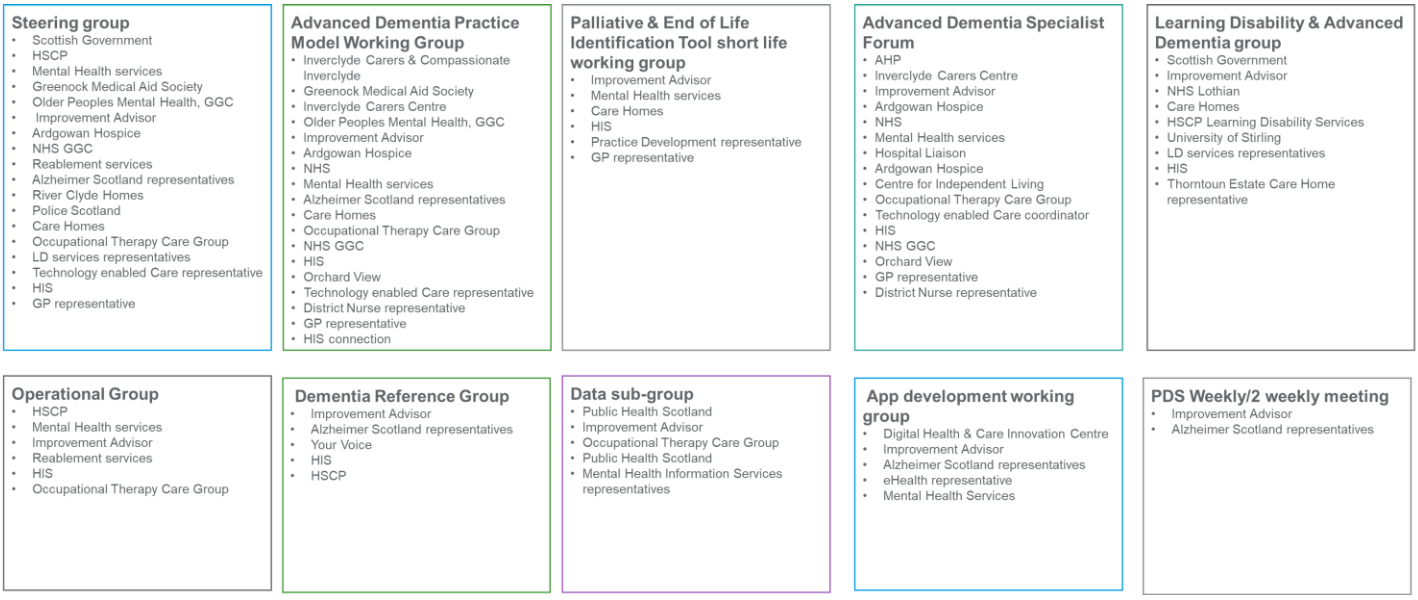
2.1.3 Programme inputs

The total programme funding was £411,713 from the Scottish Government of which £190,318 was to Focus on Dementia Healthcare Improvement Scotland. The funding related to the following two posts; NHS Greater Glasgow & Clyde Health Board Improvement Advisor and Alzheimer Scotland Public Policy Consultant. Also a Senior Improvement Advisor (quality improvement), data, measurement, evaluation and project management support were provided by Healthcare Improvement Scotland. Partnership organisations who inputted various resources (eg. staff time and expertise) into the Programme included:

- NHS GGC and Inverclyde Council as part of Inverclyde Health & Social Care Partnership (HSCP);
- Focus on Dementia team at Healthcare Improvement Scotland;
- Alzheimer Scotland; and
- Third sector partners.

Inverclyde was selected from eight applicants to be the test site for local implementation of these national policies. To support this, several working groups and sub-groups were created, including:

Figure 4: Working groups and membership



Steering group
- Scottish Government
- HSCP
- Mental Health services
- Greenock Medical Aid Society
- Older Peoples Mental Health, GGC
- Improvement Advisor
- Ardgowan Hospice
- NHS GGC
- Reablement services
- Alzheimer Scotland representatives
- River Clyde Homes
- Police Scotland
- Care Homes
- Occupational Therapy Care Group
- LD services representatives
- Technology enabled Care representative
- HIS
- GP representative

Advanced Dementia Practice Model Working Group
- Inverclyde Carers & Compassionate Inverclyde
- Greenock Medical Aid Society
- Inverclyde Carers Centre
- Older Peoples Mental Health, GGC
- Improvement Advisor
- Ardgowan Hospice
- NHS
- Mental Health services
- Alzheimer Scotland representatives
- Care Homes
- Occupational Therapy Care Group
- NHS GGC
- HIS
- Orchard View
- Technology enabled Care representative
- District Nurse representative
- GP representative
- HIS connection

Palliative & End of Life Identification Tool short life working group
- Improvement Advisor
- Mental Health services
- Care Homes
- HIS
- Practice Development representative
- GP representative

Advanced Dementia Specialist Forum
- AHP
- Inverclyde Carers Centre
- Improvement Advisor
- Ardgowan Hospice
- NHS
- Mental Health services
- Hospital Liaison
- Ardgowan Hospice
- Centre for Independent Living
- Occupational Therapy Care Group
- Technology enabled Care coordinator
- HIS
- NHS GGC
- Orchard View
- GP representative
- District Nurse representative

Learning Disability & Advanced Dementia group
- Scottish Government
- Improvement Advisor
- NHS Lothian
- Care Homes
- HSCP Learning Disability Services
- University of Stirling
- LD services representatives
- HIS
- Thorntoun Estate Care Home representative

Operational Group
- HSCP
- Mental Health services
- Improvement Advisor
- Reablement services
- HIS
- Occupational Therapy Care Group

Dementia Reference Group
- Improvement Advisor
- Alzheimer Scotland representatives
- Your Voice
- HIS
- HSCP

Data sub-group
- Public Health Scotland
- Improvement Advisor
- Occupational Therapy Care Group
- Public Health Scotland
- Mental Health Information Services representatives

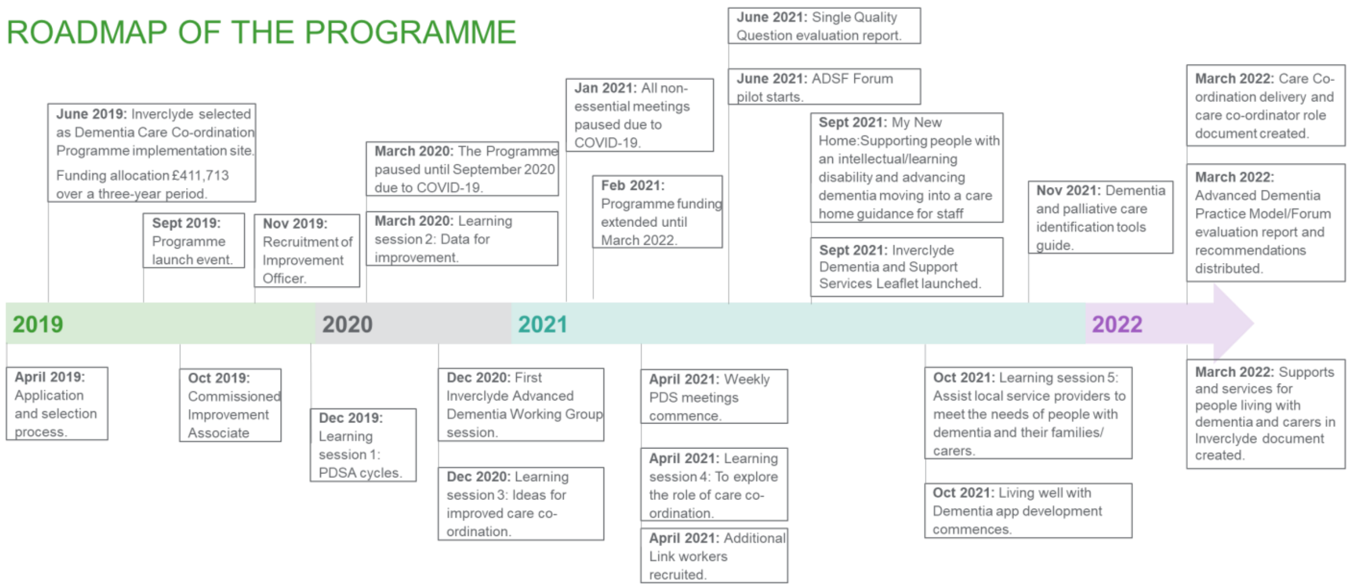
App development working group
- Digital Health & Care Innovation Centre
- Improvement Advisor
- Alzheimer Scotland representatives
- eHealth representative
- Mental Health Services

PDS Weekly/2 weekly meeting
- Improvement Advisor
- Alzheimer Scotland representatives

2.1.4 Activities undertaken and outputs

The below figure highlights activities, outputs and key events that have taken place during the Programme, evidenced from the desk review and qualitative fieldwork in the period from April 2019 to March 2022[21].

Figure 5: Roadmap of the programme



ROADMAP OF THE PROGRAMME

April 2019: Application and selection process.

June 2019: Inverclyde selected as Dementia Care Co-ordination Programme implementation site. Funding allocation £411,713 over a three-year period.

Sept 2019: Programme launch event.

Oct 2019: Commissioned Improvement Associate

Nov 2019: Recruitment of Improvement Officer.

Dec 2019: Learning session 1: PDSA cycles.

March 2020: The Programme paused until September 2020 due to COVID-19.

March 2020: Learning session 2: Data for improvement.

Dec 2020: First Inverclyde Advanced Dementia Working Group session.

Dec 2020: Learning session 3: Ideas for improved care co-ordination.

Jan 2021: All non-essential meetings paused due to COVID-19.

Feb 2021: Programme funding extended until March 2022.

April 2021: Weekly PDS meetings commence.

April 2021: Learning session 4: To explore the role of care co-ordination.

April 2021: Additional Link workers recruited.

June 2021: Single Quality Question evaluation report.

June 2021: ADSF Forum pilot starts.

Sept 2021: My New Home:Supporting people with an intellectual/learning disability and advancing dementia moving into a care home guidance for staff

Sept 2021: Inverclyde Dementia and Support Services Leaflet launched.

Oct 2021: Learning session 5: Assist local service providers to meet the needs of people with dementia and their families/ carers.

Oct 2021: Living well with Dementia app development commences.

Nov 2021: Dementia and palliative care identification tools guide.

March 2022: Care Co-ordination delivery and care co-ordinator role document created.

March 2022: Advanced Dementia Practice Model/Forum evaluation report and recommendations distributed.

March 2022: Supports and services for people living with dementia and carers in Inverclyde document created.

A number of outputs were produced throughout the programme as a result of programme activities. The below roadmap charts a person's journey through dementia from diagnosis to end of life, alongside the outputs produced and the different health and care needs associated with a dementia diagnosis:

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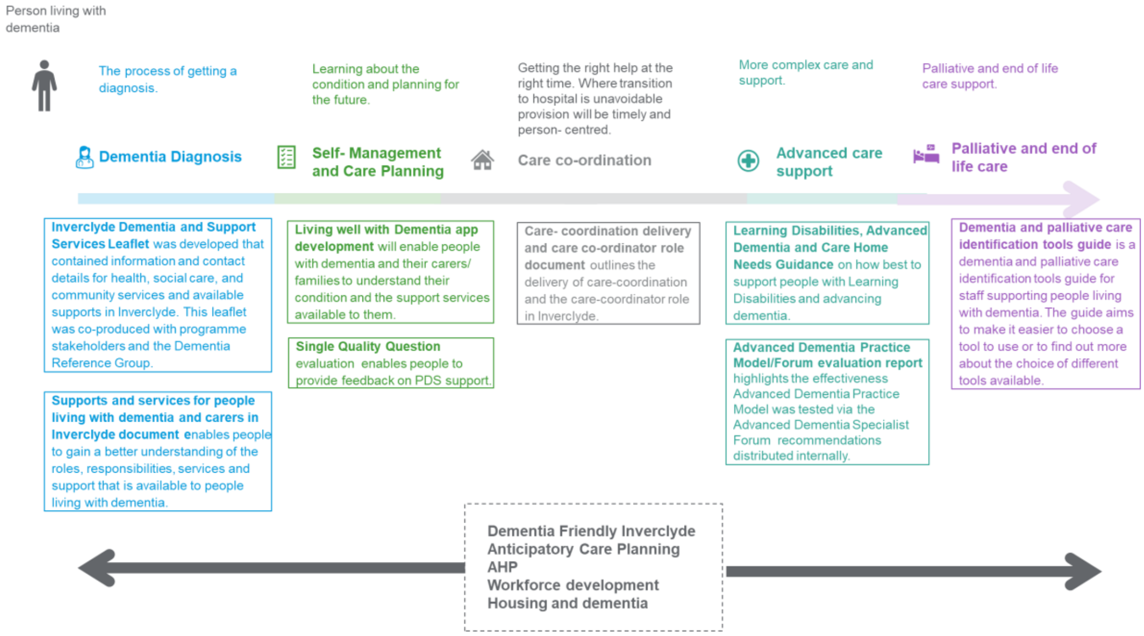
[21] The roadmap of the programme may not be a complete and comprehensive representation of the programme but highlights key activities, outputs and events described to the evaluation team through desk research and fieldwork activities.

Figure 6: Roadmap through dementia



Person living with dementia

The process of getting a diagnosis.

Dementia Diagnosis

Inverclyde Dementia and Support Services Leaflet was developed that contained information and contact details for health, social care, and community services and available supports in Inverclyde. This leaflet was co-produced with programme stakeholders and the Dementia Reference Group.

Supports and services for people living with dementia and carers in Inverclyde document enables people to gain a better understanding of the roles, responsibilities, services and support that is available to people living with dementia.

Learning about the condition and planning for the future.

Self- Management and Care Planning

Living well with Dementia app development will enable people with dementia and their carers/ families to understand their condition and the support services available to them.

Single Quality Question evaluation enables people to provide feedback on PDS support.

Getting the right help at the right time. Where transition to hospital is unavoidable provision will be timely and person- centred.

Care co-ordination

Care- coordination delivery and care co-ordinator role document outlines the delivery of care-coordination and the care-coordinator role in Inverclyde.

More complex care and support.

Advanced care support

Learning Disabilities, Advanced Dementia and Care Home Needs Guidance on how best to support people with Learning Disabilities and advancing dementia.

Advanced Dementia Practice Model/Forum evaluation report highlights the effectiveness Advanced Dementia Practice Model was tested via the Advanced Dementia Specialist Forum recommendations distributed internally.

Palliative and end of life care support.

Palliative and end of life care

Dementia and palliative care identification tools guide is a dementia and palliative care identification tools guide for staff supporting people living with dementia. The guide aims to make it easier to choose a tool to use or to find out more about the choice of different tools available.

Dementia Friendly Inverclyde
Anticipatory Care Planning
AHP
Workforce development
Housing and dementia

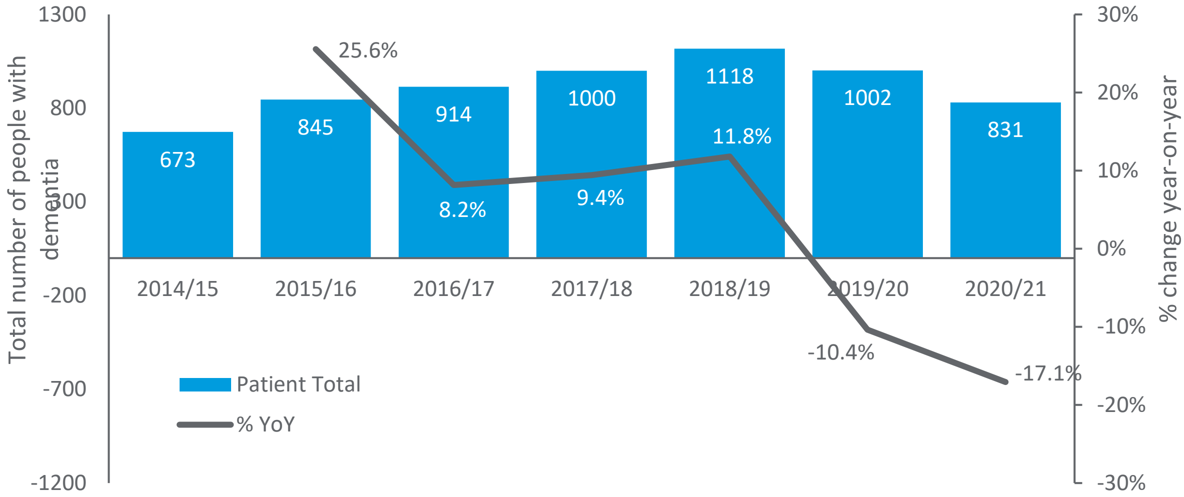
2.1.5 The profile of those receiving dementia care and support in Inverclyde

As a part of the Inverclyde Dementia Care Co-ordination Programme, a Dementia data group was expanded, whose focus has been on collating an evidence base around people living with dementia within Inverclyde. The aims of this ongoing data collection exercise were to support evidence-based decision making and inform future service planning and development, as well as monitor the impact of the programme.

Note: while the aim of this data collection is to track those people known to be living with dementia, due to the Covid-19 pandemic, it has been challenging to use this information as a benchmark for progress of the Programme. The number of people receiving a diagnosis of Dementia has been impacted by service availability throughout the pandemic.

While there is no one source for estimating the known prevalence of dementia within Inverclyde (nor a standardised process across other Scottish HSCPs), dementia prevalence has been estimated using a range of sources (eg. PDS data, social care data, care home census, prescribing data etc.) by Public Health Scotland and scrutinised for double counting to generate the below datapoints (from Figure 7 to Figure 9).

Figure 7: Number of people living with dementia (left axis) and the percentage change year-on-year (right axis)



Source: Public Health Scotland

The estimated number of people being treated for dementia in Inverclyde rose to a peak in 2018/19 (a total of 1,118). This number has decreased since the start of the programme in 2019/20 (and subsequently in 2020/21). The Covid-19 pandemic has impacted upon the number of people being diagnosed and excess deaths[22] and while this is challenging to quantify, there is evidence to support disruptions to diagnostic processes during the pandemic[23].

> *"As a result of restrictions, the pandemic has reduced people's likelihood of getting a timely diagnosis (with variation across Scotland because of the pandemic in the delivery of diagnostic scans in particular) and their opportunity to participate in our person centred post diagnostic support, particularly where peer support in groups was what they preferred."*[24]

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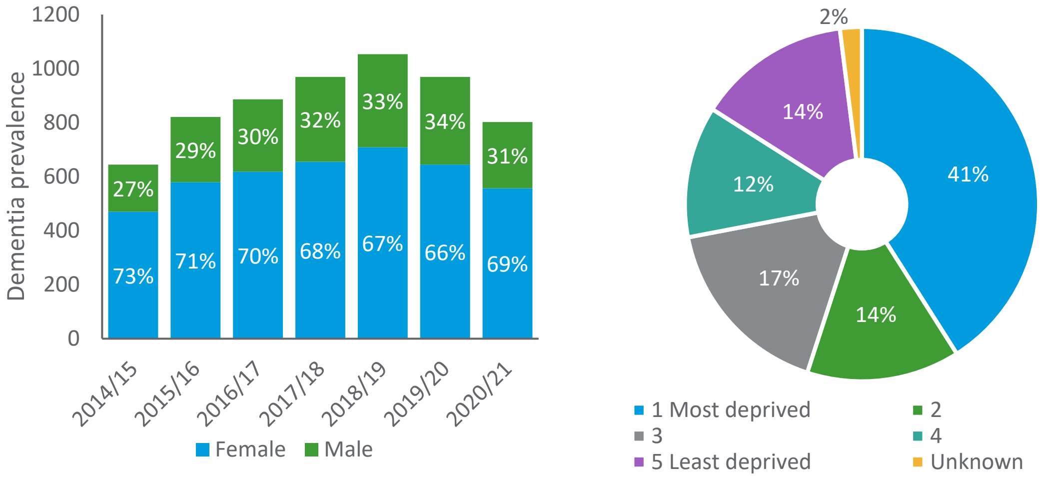
[22] 95% of people with dementia who died between 16th March and 31st December 2020 (2,038 deaths) were registered with COVID-19 as the main underlying cause (Source: Scottish Government (2022) Excess deaths from all causes and dementia by setting Scotland 2020-2021).

[23] Estimated and Projected Diagnosis Rates for Dementia in Scotland: 2014-2020 (alzscot.org)

[24] Scottish Government (2021) Coronavirus (COVID-19) - dementia and COVID-19: action plan. Available at: https://www.gov.scot/publications/dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers/documents/

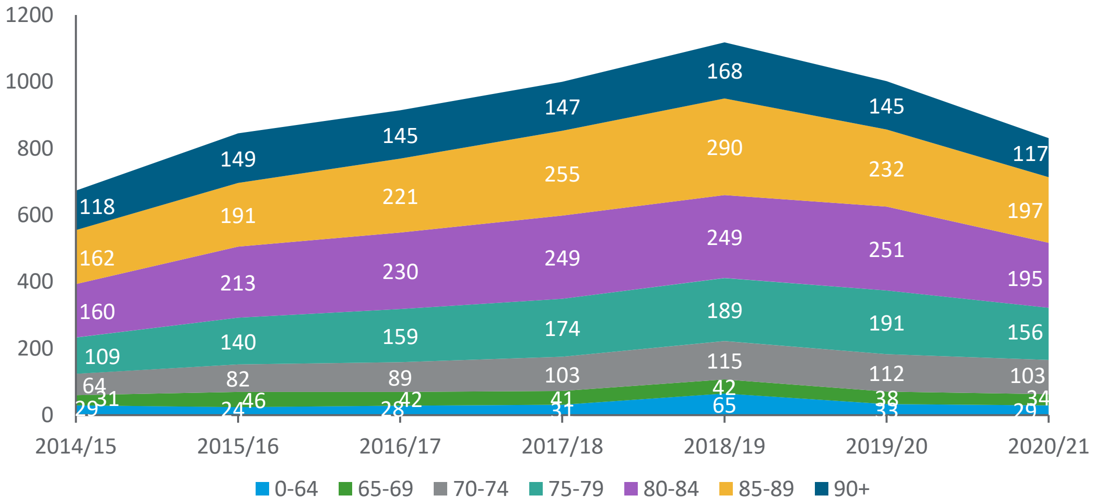
Figure 8: Proportion of people with dementia by gender for those diagnosed with dementia aged 65+ (left) and Total dementia referrals by Scottish Index of Multiple Deprivation[25] (right)



Source: Public Health Scotland (left) and Inverclyde HSCP (right)

When considering the gender of those who are being treated for dementia, just over two-thirds of those who have a diagnosis are female (fluctuating between 66-73% depending on year). When considering deprivation levels, a significant proportion (41%) of dementia referrals to PDS are also from those householders who live in the top 20% most deprived data zones in Scotland. However, it should also be noted that the proportion of datazones in Inverclyde in the top two Scottish Index of Multiple Deprivation (SIMD) quintiles is also high (44%).

Figure 9: Proportion of people with dementia by age



Source: Public Health Scotland

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[25] Based on data total referrals from 2016/17 and 2019/20 (from Inverclyde Dementia Care Co-ordination Programme Baseline Data Summary March 2020).

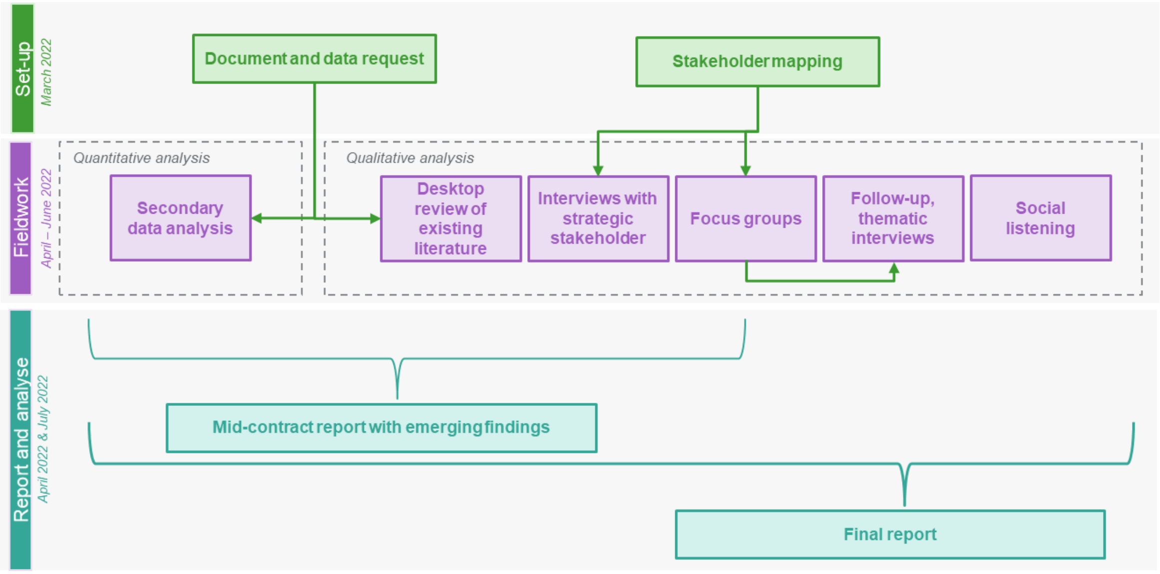
There has also been analysis undertaken to understand the age cohorts of the (known) population living with dementia in Inverclyde, which has been presented above in Figure 9. The proportions of people known to be living with dementia by age do not vary significantly over time.

Overall, the number of people diagnosed with dementia peaked at 1,118 in 18/19, then declined (most likely due to service interruption during the Covid-19 pandemic). Data indicates that those treated for dementia in Inverclyde have typically been more likely to be female, but that there has been little change over time in the age profile.

3. METHODOLOGY

RSM UK Consulting LLP (RSM) and Dr Barbara Sharp[26] were commissioned by the Scottish Government in February 2022 to conduct an independent evaluation of the Dementia Whole-System Care Coordination Programme in Inverclyde Health and Social Care Partnership (HSCP). A mixed-methods approach has been adopted for this evaluation, combining both qualitative and quantitative research approaches. The diagram within Figure 10 provides an overview of our approach and how these will come together to inform the evaluation outputs.

Figure 10: Overview of methodology



Quantitative research

Secondary analysis of existing data and programme information has been used to evidence outcomes against the outcomes for the Programme. Document and data were identified via discussions with representatives from organisations involved in the delivery of the programme. Data that has been collated and reviewed as a part of this analysis has included:

- Inverclyde HSCP (2020) Inverclyde Dementia Care Co-ordination Programme: Baseline Data Summary March 2020;
- Dementia Prevalence data (Source: Public Health Scotland); and
- PDS Referrals, Waiting List and Caseload data (Source: Inverclyde HSCP)

Qualitative research

Desktop review

From the documents received (including flash reports, progress reports, the PDS quality framework, programme action plan and Focus on Dementia Newsletters), we have undertaken a review to build together the story of the Programme. A breakdown of the documents received is

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[26] The RSM team worked in conjunction with an academic advisor, Dr Barbara Sharp, who provided subject matter expertise upon request, and provided review and commentary on our draft findings and report.

available in the annex. Using the evaluation framework in Annex 9, we have considered evidence related to the activities of the programme, the outputs and outcomes.

Interviews with strategic stakeholders

The purpose of these interviews is to understand the wider context in which the programme is being delivered, the expectations of the programme from strategic stakeholders, test out their knowledge of the work to date and garner reflections on what the future should look like. Interviews included representation from Healthcare Improvement Scotland, Inverclyde HSCP, Inverclyde Council, Convention Of Scottish Local Authorities (COSLA), and the Scottish Government. In total, **seven** virtual interviews have taken place. The topic guide is contained in the annex.

Reflective focus groups with key stakeholder groups

Eight reflective online focus groups were held with operational delivery groups (x3), specialist and lived experience groups (x3) and steering group members (x2). In total, there were 23 participants in focus groups (each focus group had a minimum of two participants, and the largest focus group had five participants). These discussions were held between April and June 2022, lasting approximately 90 minutes each. The topic guide is contained in the annex.

Follow up interviews

Five follow-up virtual interviews were held with representatives from the app development team, AHP team and from a programme sustainability perspective, to deep dive into specific thematic areas and examples of success, innovation or best practice. Specific questions were developed for each follow-up interview.

Social listening and observation at programme events

To explore ongoing communications about the work of the programme, the team attended **three** social listening events. These included the Inverclyde Dementia Care Co-Ordination final webinar (30th March 2022), attendance at the Data Reference Group (May 2022) and the Local Dementia Strategy Group (June 2022).

Analysis and triangulation of findings

Detailed notes were taken for all focus groups and interviews with stakeholders and reviewed and analysed descriptively and thematically.

Limitations

- As the evaluation was conducted after the Programme ended, some of the staff involved in the programme are no longer in post, meaning that their views could not be captured. The evaluation team sought to engage as many staff members as possible in evaluation activities (as indicated above, 23 individuals took part in focus groups, of which 21 were staff), however, this was not always possible due to conflicting priorities and service delivery pressures.
- Gaining the involvement of those living with dementia and their carers was a challenge due to the ongoing impacts of the Covid-19 pandemic (eg. shielding or the closure of services) on this community. We were able to speak to four individuals who identified as carers of people with dementia (or as having a caring role) as part of this evaluation.
- The summative nature of this evaluation limited the ability to evaluate each individual workstream of the Dementia Care Co-ordination Programme in detail. A formative evaluation would allow for a more thorough assessment of the implementation process throughout the full timeframe for programme delivery and might have allowed for ongoing learning to be captured more holistically over the three-year period (eg. on how well the Programme structures worked or engaging with staff throughout the development and implementation of the various approaches).
- The majority of quantitative measures within the outcome and monitoring framework were perceived by the evaluation team to be outputs rather than outcomes (eg. the number of people receiving PDS was stated as an outcome rather than an output). Again, this might be helped by formative evaluation whereby an evaluation team reviews measures within the outcome and monitoring framework at the outset, comparing these with the Theory of Change and ability to quantify change within the programme/ evaluation timeframes.

4. OUTCOMES AND IMPACT OF THE PROGRAMME

This section of the report provides an overview of how the Inverclyde Dementia whole-system care co-ordination Programme has met its intended outcomes. The impact of the Programme has been evidenced against the four overarching outcomes for the Programme (see introduction) which have been aligned to the Theory of Change (see Annex 1).

This section is evidenced through a range of desk review, secondary data analysis and qualitative research. Qualitative research included:

- Seven virtual interviews with strategic stakeholders including representation from Healthcare Improvement Scotland, HSCP, Inverclyde Council, Convention Of Scottish Local Authorities (COSLA), and the Scottish Government;
- Eight reflective focus groups, with operational delivery groups (x3), specialist and lived experience groups (x3) and steering group members (x2);
- Five follow-up interviews to deep dive into specific thematic areas; and
- Attendance at three social listening events.

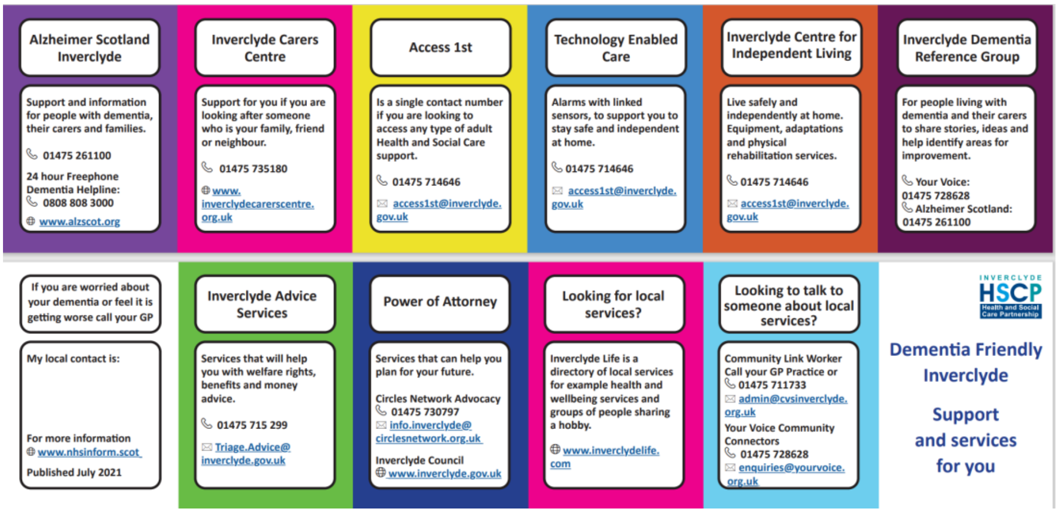
4.1 Outcome 1: A personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer.

This overarching outcome links to a number of areas identified within the Theory of Change, including people living with dementia are supported to live independently, and are connected and valued in their communities.

4.1.1 Findings from the desktop review and secondary data analysis

One of the activities of the Programme has been to develop a leaflet providing contact information for dementia support services to people living with dementia and their families/ carers. The purpose of this leaflet (see below) is to support people with dementia to stay connected to their local community and to self-manage. This leaflet was co-produced with people living with dementia and families in the Inverclyde Dementia Reference Group and launched on World Alzheimer’s Day (September 2021).

Figure 11: Dementia Support Services leaflet[27]



Alzheimer Scotland Inverclyde

Support and information for people with dementia, their carers and families.

☎ 01475 261100

24 hour Freephone Dementia Helpline:
☎ 0808 808 3000

🌐 www.alzscot.org

Inverclyde Carers Centre

Support for you if you are looking after someone who is your family, friend or neighbour.

☎ 01475 735180

🌐 www.inverclydecarerscentre.org.uk

Access 1st

Is a single contact number if you are looking to access any type of adult Health and Social Care support.

☎ 01475 714646

✉ access1st@inverclyde.gov.uk

Technology Enabled Care

Alarms with linked sensors, to support you to stay safe and independent at home.

☎ 01475 714646

✉ access1st@inverclyde.gov.uk

Inverclyde Centre for Independent Living

Live safely and independently at home. Equipment, adaptations and physical rehabilitation services.

☎ 01475 714646

✉ access1st@inverclyde.gov.uk

Inverclyde Dementia Reference Group

For people living with dementia and their carers to share stories, ideas and help identify areas for improvement.

☎ Your Voice:
01475 728628
☎ Alzheimer Scotland:
01475 261100

If you are worried about your dementia or feel it is getting worse call your GP

My local contact is:

For more information
🌐 www.nhsinform.scot

Published July 2021

Inverclyde Advice Services

Services that will help you with welfare rights, benefits and money advice.

☎ 01475 715 299

✉ Triage.Advice@inverclyde.gov.uk

Power of Attorney

Services that can help you plan for your future.

Circles Network Advocacy
☎ 01475 730797
✉ info.inverclyde@circlesnetwork.org.uk

Inverclyde Council
🌐 www.inverclyde.gov.uk

Looking for local services?

Inverclyde Life is a directory of local services for example health and wellbeing services and groups of people sharing a hobby.

🌐 www.inverclydelife.com

Looking to talk to someone about local services?

Community Link Worker
Call your GP Practice or
☎ 01475 711733
✉ admin@cvsinverclyde.org.uk
Your Voice Community Connectors
☎ 01475 728628
✉ enquiries@yourvoice.org.uk

INVERCLYDE HSCP Health and Social Care Partnership

Dementia Friendly Inverclyde

Support and services for you

Post Diagnostic Support (PDS) link workers provide personalised care and approaches to people diagnosed with dementia, to enable them to self-manage and live independently for longer. Weekly PDS staff meetings, led by the Older People's Mental Health team lead, have also been set up as a part of the programme, which provide support to PDS Link Workers as a means of proactively reviewing the PDS service waiting list, waiting times and current PDS Link Worker's caseload. An internal evaluation[28] of the PDS weekly meetings was undertaken, with feedback on the sessions from PDS Link Workers collected via a survey. The evaluation findings suggest that these weekly meetings support the implementation of personalised care through link workers sharing good practice (eg. obtaining guidance on difficult cases or situations). These meetings have also been beneficial for promoting inter-agency collaboration.

From the quantitative data provided (see figure below), there is also evidence that waiting list times were decreasing at the start of the Programme (September 2019 – February 2020), however, waiting times began to rise at the start of the pandemic. In September 2020, there was a small rise in waiting times until November 2020 (mean of 219.6 days), however, there has been on an overall downwards trend. Fluctuations in the waiting list times for PDS were partially driven by the PDS related activity and the increased number of link workers in the Programme.

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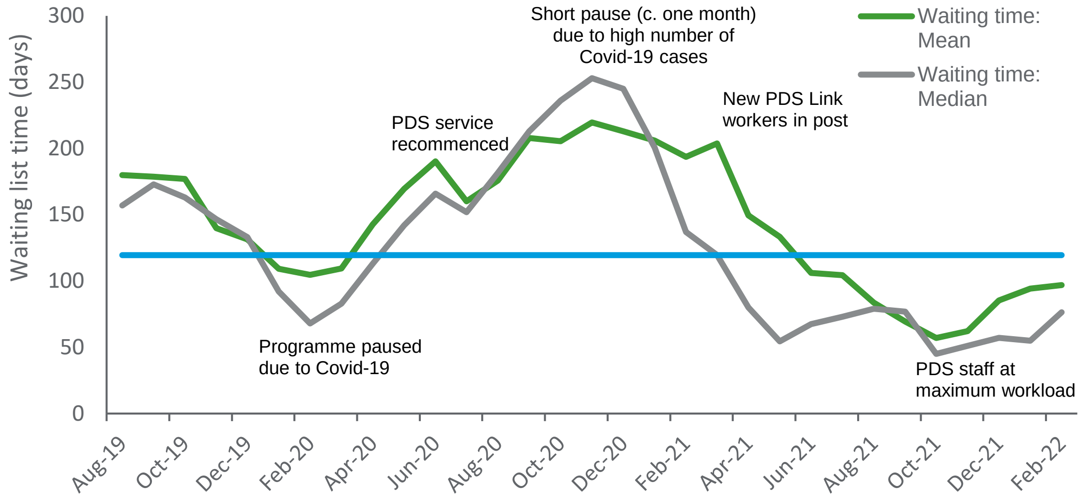
[27] https://www.inverclyde.gov.uk/assets/attach/14316/Inverclyde-Dementia-Support-and-Services-FINAL.pdf

[28] Inverclyde Dementia Care Co-ordination Programme (July 2021) Evaluation of Post Diagnostic Support (PDS) Service Weekly Meetings

Figure 12: Waiting list times for PDS



Source: Inverclyde HSCP

To support the provision of appropriate care for those people living with **advanced dementia** or requiring palliative care, an Advanced Dementia Specialist Forum (ADSF) was piloted in Inverclyde, with an evaluation of the ADSF undertaken internally, highlighting strong multidisciplinary and multi-agency working which service providers reflected on positively. It has been acknowledged within the evaluation report[29] that it is important to ensure that people with advanced dementia have their care needs recognised and met. When these needs are not being met, input from the Advanced Dementia Specialist Team via the ADSF is recommended. While the internal evaluation has identified that only three cases have been escalated to the ADSF, feedback from the evaluation suggests that it provides value in addressing any unmet needs, and more widely this approach also supports collaboration and multiagency working through the number of different professions and organisations involved in the forum.

4.1.2 Findings from qualitative engagement

Stakeholders considered improvements in PDS delivery to be a particularly positive aspect of the Programme. Focus group participants reported that increased PDS link worker resource contributed to reduced PDS waiting lists, meaning individuals were receiving early dementia care, enabling them to better self-manage; *"you can quite clearly compare the wait times before we got the additional link worker resource to when we got the additional resource. The waiting times reduced dramatically" (focus group participant).* This view was endorsed by strategic stakeholders: *"if people get a timely diagnosis early in the disease process, it helps them understand their illness, to think about planning for the future and to give them opportunities for peer support and to be connected into the wider community" (strategic stakeholder).*

Both staff members involved in delivery and stakeholders regarded the presence of link workers as important in providing tailored care, as well as a point of contact for people with dementia and their carers. Focus group participants highlighted that link workers are able to signpost those with

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[29] Inverclyde Dementia Care Co-ordination Programme (March 2022) Evaluation of the Advanced Dementia Specialist Forum

dementia to appropriate support services and information sources, which should lead to improved outcomes for people living with dementia (however it has not been possible to quantify the extent to which outcomes have improved through the evaluation); *"I think what [the link worker] does is achieve better outcomes for everyone going through that service and actually getting the support that they need" (focus group participant).* The link worker role was also identified as key in building the confidence of people living with dementia to self-manage their condition and live independently for longer; *"the link workers role is…to help build natural networks and support around them and build their resilience and confidence to live as well as possible" (focus group participant).* However, current data outlining these improved outcomes is currently limited.

In addition, the sharing of link workers' specialist knowledge of dementia with other staff members was regarded as a positive; *"we [health and social care staff] have learned from them and they have learned from us... this is not typically how it operates in other areas."* Within Inverclyde, link workers were co-located with the Older Adult Community Mental Health Teams (OACMHT), further reinforcing positive links with system partners. Stakeholders highlighted that ensuring that there was sufficient home care available for those with dementia was also important in preventing people from going into residential care earlier than expected.

One stakeholder suggested that this impact may take some time to embed, as this partnership working approach will require a degree of cultural change; *"What we're talking about here is a culture change. A culture shift from separate component parts to working together…it's about how you develop the relationships across…the system to get that in depth understanding so that I can say I know how to support you to get that crucial bit of service that you need that will help you to stay in your own home for longer" (strategic stakeholder).*

Stakeholders noted that initiatives such as ongoing work to make Inverclyde a Dementia Friendly Community are also key to drawing Dementia into the wider strategic agenda and raising awareness of services available to enable people living with dementia to live independently for longer; *"these wider pieces of work also impact those with dementia" (strategic stakeholder).*

4.2 Outcome 2: A better person experience, improved quality and better outcomes for people in the area living with dementia and their carers

This outcome links to a number of areas within the Theory of Change, related both to staff (eg. staff supporting people living with dementia and their carers understand each other's services, roles and responsibilities) and people living with dementia and their families/carers (eg. people with dementia and their carers feel they have the opportunity to inform service improvement).

4.2.1 Findings from the desktop review and secondary data analysis

One of the outlined activities within the Theory of Change was to test and collect data for improvement. As a part of the programme, the testing of a single quality question that can be asked of people with dementia and their families/ carers was undertaken. This question will allow people living with dementia and their families/ carers to provide feedback and capture evidence relating to the impact of PDS. This single quality question[30] (*Please tell us, overall, how helpful or unhelpful the support has been to you?)* has now been implemented to ensure that the PDS service is providing a better person experience. Examples of the qualitative feedback from the single quality question are reported on in Alzheimer Scotland Post Diagnostic Support Service report[31].

The weekly PDS meetings and the ADPM/ ADSF will also likely contribute to this outcome. While there is evidence of positive outcomes for staff (see 3.1.1), as these activities are not tangible to people with dementia and their families, it is difficult to quantify the impact of these activities, without wider quantitative outcome data being available. A new process that commenced through the Programme, is the annual assessment of whether each of the 12 critical success factors[32] which have been identified for dementia care are being met through dementia services in Inverclyde. This year, Inverclyde Dementia Care Co-ordination programme evidenced that the success factor for *Promoting independence and quality of life* has been met, with a summary of their rationale/evidence below:

- The use of Community Link Workers;
- Provision of hospice care and Compassionate Inverclyde initiatives;
- Identify who may be at risk of loneliness and need further support;
- All of the rehab and enablement that takes place within Inverclyde; and
- use of third sector and community and voluntary organisations.

Out of the 12 critical success factors developed, in the annual review of services, it was determined that nine had been achieved, with single point of access; self-referral when things change and use of quality improvement the factors identified as areas that could be improved.

4.2.2 Findings from qualitative engagement

One key stakeholder suggested that the programme's focus on joined-up care was a key step in providing quality care for those living with dementia. Since staff were now more aware of services available locally, they could refer those living with dementia to services at an earlier stage of their condition, leading to more positive outcomes; *"you can't underestimate importance of early care within first few weeks… awareness of what's out there means that fewer people get lost in the system that way" (strategic stakeholder).*

Focus group participants acknowledged that prior to the programme, care-ordination and the integration of services was good within Inverclyde *"there were a lot of good things happening and they continue to happen" (focus group participant).* Staff suggested that co-ordination of PDS support in the immediate period post-diagnosis was a particular strength; *"the 5 Pillar Model of PDS that has been implemented…that has been fairly robust" (focus group participant)*. Staff also suggested that those with both a learning disability and more advanced dementia were less likely to experience gaps in their care beyond the initial period of PDS due to the work of the Learning

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[30] HIS and Alzheimer Scotland (2021) Testing the feasibility and usability of a post-diagnostic support single quality question. Available at: Who we are, what we do (ihub.scot)
[31] Alzheimer Scotland Post Diagnostic Support Service (PDS) – Inverclyde – Report April 2021 – March 2022
[32] 12 critical success factors for effective care co-ordination for people living with dementia and their families/ carers were identified by Healthcare Improvement Scotland and implemented within Inverclyde. These factors are available here: 20190516 critical success factors A4 (ihub.scot)

Disability and Advanced Dementia team; "*in learning disability because of multidisciplinary teams, there's not such a gap probably for people because, they do have that ongoing network and contact…their learning disability nurse would continue to be involved with them" (focus group participant).*

However, focus group participants noted that no significant improvements to gaps in care co-ordination for those with more advanced dementia were achieved as a result of the Programme; *"it's more that front end, the PDS workers are very much part of this team…but I'm not sure in terms of everything else that the programme's made much of a difference" (focus group participant).* Focus group participants queried the value of the Advanced Dementia Practice Model, highlighting significant overlap between the model and the care management already established within Inverclyde; *"the advanced practice model that they used…I think for us and Inverclyde, it was quite difficult to tease that because we already have care management" (focus group participant).* Staff highlighted difficulties in translating the model into practice and suggested that the model would have been more appropriate for end of life care; *"the whole advanced practice model…it was more like an end of life care model as opposed to advanced dementia, which it's two different things" (focus group participant)*. [33]As a result, more time will be required to embed the model amongst staff members.

Despite the limited opportunities for face-to-face events during the Covid-19 pandemic where people living with dementia, their families and carers would previously provide input, focus group participants commented that the programme remained committed to incorporating their views; *"It's not like we haven't continued to have contact with families and service users during Covid-19, we have. But it's just…it's been harder to get them to participate in some of this stuff around the edges because they've been just surviving day-to-day" (focus group participant).* Focus group participants outlined how the Dementia Reference Group was vital in ensuring that the views of those with lived experience, their families and carers were incorporated into the programme, to ensure that the programme remained as relevant as possible.

The Dementia Reference Group played an integral role in the development of the programme leaflet which provides people living with dementia, their families and carers with information on local services and support available; *"the Dementia Reference Group was significantly involved in that leaflet, and how it looked and what it had on it" (focus group participant).* Those involved in the development of the leaflet indicated that it was well received by people living with dementia, their families and carers, and contributed to improved access to dementia services, ultimately leading to better outcomes; *"The leaflet that was devised was really good, it was concise and gave the essential points without being bombarded. That has generated people getting in touch with other organisations" (focus group participant).*

One stakeholder highlighted that the development of the Living Well with Dementia app (currently being tested prior to full release) will be beneficial for supporting those with dementia, and that the Dementia Reference Group had also played an active role in developing this to improve user experience; *"there's the technology part and making sure it's correct, you know the font size and even the colours as well of what's on screen, we have to be careful when someone's experiencing dementia" (focus group participant)*. This app (developed in collaboration with

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[33] As outlined on page 29, the ADSF evaluation indicated high levels of multidisciplinary and multi-agency working within Inverclyde

Inverclyde Health and Social Care Partnership, Alzheimer Scotland, Healthcare Improvement Scotland, the Digital Health & Care Innovation Centre and NHS Greater Glasgow and Clyde) is intended to help those living with dementia to identify what is important for them, any changes in their daily lives and any support that may be required. However, some focus group participants indicated that whilst the outputs of the programme are tangible, more time will be required to measure outcomes; *"the outputs are quite visible, but the outcomes are not" (focus group participant).*

Others commented that work to make Inverclyde a dementia-friendly community was a key strand of the programme, as it brought a greater awareness of dementia to the wider population, as well as practical measures to support those living with dementia, their families and carers in the community.

4.3 Outcome 3: A more integrated and co-ordinated approach across the whole system which enhances connections and improves collaboration across health and social care

This outcome links to a number of areas within the Theory of Change, particularly in relation to staff. For example, staff know how to signpost and refer to each other's services including the Third Sector, staff know which other services are supporting people living with Dementia and their carers' and, staff develop positive relationships across teams.

4.3.1 Findings from the desktop review and secondary data analysis

In a Programme report that outlined the benefits of care co-ordination[34], the following definition of care co-ordination was put forward. This was complemented by a learning session, which focused on defining and understanding the care coordinator role. Having a single definition that is utilised across staff working in dementia services within Inverclyde may help provide a common understanding amongst professionals.

> *"a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings".*[35]

As a part of the programme, there have been five learning sessions (between late 2019 and late 2021) which have taken place for staff (representatives from local and national organisations across Inverclyde HSCP), relating to improving care co-ordination for people with dementia and their families. There has been positive initial feedback (see below) from the staff who have attended these care co-ordination learning sessions, with evidence suggesting that there has been value in these sessions and that the knowledge and understanding relating to care co-ordination has improved. The majority of the feedback collected from these sessions relates to satisfaction levels and improved knowledge, however, there was limited evidence on how staff

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[34] Inverclyde Dementia Care Co-ordination Programme (October 2020) Key benefits of dementia care co-ordination

[35] WHO (2018) Continuity and coordination of care: a practice brief to support implementation of the World Health Organization (WHO) Framework on integrated people-centred health services. 2018. Geneva, World Health Organization. Available here.

have put the learning into action to make an impact on care delivered, based on the good practice of the Kirkpatrick model of evaluating learning-based interventions.[36]

Table 1: Summary of learning event information

Event	Attendance	What the session covered	Feedback
LS1 (Dec 19)	39 staff	PDSA cycles	• 90% of attendees rating the event as good or very good • Enjoyed discussion with other professionals and the practical session on QI
LS2 (Mar 20)	64 staff	Data for improvement	• 92% of attendees rating the event as good or very good. • Valued in national perspective and how this work is being implemented locally.
LS3 (Dec 20)	25 staff	Ideas for improved care co-ordination	• Positive feedback on GP case study and provided good opportunity for discussion
LS4 (Apr 21)	51 staff	To explore the role of care co-ordination	• 99% agreed they were confident about what care co-ordination is • 62% agreed their knowledge and understanding of care co-ordination has improved
LS5 (Oct 21)	49 staff	Assist local service providers to meet the needs of people with dementia and their families/ carers	• 93% agreed or strongly agreed that they understand the roles and responsibilities of the different services • 93% agreed or strongly agreed that they know how to refer to the other services.

In additional to the care co-ordination learning events, there has been a series of guidance documentation, such as Defining Dementia Care Co-ordinator Role in Inverclyde (March 2022), which have also been developed to support care co-ordination within Dementia care in Inverclyde.

Within the annual Alzheimer Scotland Post Diagnostic Support Service Inverclyde Report (April 2021 – March 2022), there was some data provided on the activities conducted by link workers during PDS. From this data, we can see that link workers conducted a number of contacts with other professionals (eg. GPs, AHPs etc.) and referrals were made to external agencies (eg. the Voluntary and Independent sector) as a part of the PDS support activities.

Table 2: Summary of link worker activity (April 2021 – March 2022)

Contact with other professionals	Referrals made to external agencies	Face to face meetings with PWD/family carer	Number of calls to PWD/family carer
516	421	260	1877

A range of measures were requested as a part of the evaluation in March 2022, which aimed at gaining a greater understanding of how dementia care is co-ordinated and what services are provided to individuals (ie. by primary care, the community and voluntary sector etc.). Presently

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[36] The Kirkpatrick Model (kirkpatrickpartners.com)

this data exists within the individual care records of each person with dementia but is difficult to extract for secondary analysis (due to patient confidentially).

4.3.2 Findings from qualitative engagement

All those interviewed highlighted that there was a strong existing culture of integration within Inverclyde, which was a key component in facilitating collaborative working, particularly with third sector partners *“Inverclyde has a strong connection with its third sector partners… we had buy-in from people across the area” (thematic interview).*

A number of strategic stakeholders interviewed outlined how strong and visible leadership within Inverclyde was positive for developing positive relationships with carers (ie in increasing the programme’s visibility), and partnership working (ie sustaining the pre-existing collaborative culture). The introduction of an improvement advisor for the programme, within Inverclyde HSCP was referenced as being a key enabler*; "Having a project improvement advisor was absolutely critical" (focus group participant).* In addition, the establishment of the Inverclyde Programme Steering Group and consultation of the Dementia Reference Group as part of the programme were considered to be supportive of this co-ordinated approach, allowing for the identification of barriers and support mechanisms for those living with dementia.

Others suggested the shared use of systems facilitated collaboration amongst the Inverclyde team. For example, providing link workers with access to records (such as mental health service EMIS,) cemented this integrated relationship, as it indicated that they were *“real partners within the team” (strategic stakeholder).*

Collaborative learning opportunities (such as learning sessions & associated flash reports) ensured all partners were more aware of services on offer within the local region and had a good understanding of each partners’ roles and responsibilities; *“flash reports were released periodically, and I guess that was quite helpful” (focus group participant).*

A number of stakeholders suggested that high levels of collaboration were particularly positive given the context of Covid-19; *“People still spoke to one another. We still communicated, they still care managed people with different professionals and different teams all that continued” (strategic stakeholder).*

However, some focus group participants acknowledged that whilst good practice exists within Inverclyde, there remains scope for this co-ordination to be further improved *“as a wide sweeping brush stroke, I'm not sure we could say that the systems [are] you know perfectly cohesive and joined up” (focus group participant).* Carers suggested that it was too early to determine if care was more integrated; *“It’s too early to say [if the care and services offered] are more integrated or coordinated” (focus group participant).* As a result of the disruption to care and support services during the Covid-19 pandemic, more time is required to fully evidence the impact of the programme on those with dementia and their families/ carers. In addition, the input from those with lived experience and their carers into this evaluation was limited - further consultation of those with lived experience and their families/ carers where possible would be beneficial in evidencing impacts.

4.4 Outcome 4: Effective monitoring and measurement approaches that can adequately assess the effectiveness and quality of the 'whole system' locality approach.

This outcome is cross-cutting across all of the outcomes identified within the Theory of Change.

4.4.1 Findings from the desktop review and secondary data analysis

Throughout the programme, there has been evidence of ongoing feedback and monitoring, related to the progress of the programme activities (via input into monthly progress reports to HIS) and the monitoring and evaluation of a range of different programme areas. There have been a number of internal evaluations which have taken place across different areas of the programme. These internal evaluations have included receiving feedback from people with dementia and their families and staff via feedback forms and reflective sessions.

Table 3: Summary of internal evaluations

Evaluation	**Date**	**Methodology**
Post Diagnostic Support (PDS) Service Weekly Meetings	July 2021	Survey of staff who attended PDS meetings (six staff)
The single quality question format	June 2021	28 people were interviewed over a two-week period
Advanced Dementia Specialist Forum	March 2022	• Reflections from the ADST following the first ADSF; • Reflections from person presenting the case directly following the ADSF and 3 – 4 weeks follow up; • Online reflective questionnaire; • Face to face reflective session; and • Feedback from Inverclyde GP Forum.
Services & Supports Leaflet	Date unknown	Survey with two people with dementia and six carers

Alongside the evaluation and the progress update to Scottish Government, a data measurement and performance framework has been developed. This plan provides the reporting schedule (see below) for the frequency at which data will be reviewed for the programme. From the reporting schedule, evidence has been shared on the annual benchmarking of the 12 Critical Success Factors which has been undertaken. This provides some qualitative information as to what extent that the services that the Programme has been supporting are meeting the other three overarching outcomes.

Table 4: Schedule for report monitoring

Reporting Schedule	Frequency
Quality and Performance reporting	Monthly reports; Quarterly meetings
Commissioning data sets	Monthly reports
Benchmarking of 12 CSF	Annually
Annual summary & assessment report	Annually

A Theory of Change for the programme was developed in April 2021, outlining the inputs, activities and outcomes of the programme. This framework contains significant detail relating to the intended outcomes of the programme (see Annex 1 for outcomes); with information on the measures included within the Measurement and Performance framework and the Reporting Schedule (see above).

Based on a review of the Theory of Change and the overarching outcomes for the programme, whilst overall there is alignment between these two sets of outcomes, there is some complexity when trying to group the intended outcomes (ie. many of the intended outcomes could fall under multiple or all of the overarching outcomes (see example below)). It has been identified through the evaluation that there may be scope to streamline the outcomes on a thematic basis, for example, grouping outcomes related to the improved quality of care.

In terms of quantitative monitoring data for dementia services, there is currently sufficient data related to the outputs of the programme, for example, referrals, numbers receiving support etc. There has been significant work throughout the Programme to create a methodology to collect this data across multiple organisations within the local system, given there is no one central data point for people living with dementia. However, there is limited data collected on outcomes such as a person's ability to self-manage and live independently for longer. While there has been consideration from the programme into what can be measured at a local level (via the Measurement and Performance Framework which outcomes of the programme were measured against) the majority of the quantitative measures are mostly focussed on outputs. To be able to further improve the evidence relating to the impact of the programme, the development of standardised dementia outcomes measures may want to be considered at a national level (eg. by Scottish Government), so that local systems are able to better understand the impact of the dementia services provided.

The next steps for dementia data collection and monitoring are to develop a dementia register. This work commenced in April 2022 via Inverclyde HSCP Quality and Development services, with support from Public Health Scotland and Scottish Government, with work ongoing[37]. This register will contain information on people with dementia in Inverclyde, including diagnosis, living circumstances, carers, services provided, hospital admissions, end of life care. The benefits of this register have been identified by the programme team include:

- A warehouse of local historical data of Inverclyde population of people with a formal Dementia diagnosis;
- Development of baseline information to generate demographic reporting;

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[37] Inverclyde HSCP (n.d.) Dementia Register

- To improve knowledge of the local population;
- Aid evaluation and planning of service provision;
- Provide a baseline to build trajectory reports including levels of care and costs; and
- To contain information for performance reporting.

4.4.2 Findings from qualitative engagement

Stakeholders and focus group participants outlined that a key benefit of the programme was collating and analysing data (such as acute data) in a systematic manner. As one focus group participant commented, *“data is an important part of proving what has been done and helping to plan what will be done… data helps to support delivery and target the biggest impact with the resources available” (focus group participant).*

Overall, having strong data has been useful in evidencing the impacts of the programme, for example comparing waiting times for post diagnostic support pre and post introduction of link workers, and for planning future services. Stakeholders welcomed Scottish Government funding for the analyst role, as it increased data analysis capacity within Inverclyde.

Staff welcomed the introduction of flash reports (including learning session and steering group reports), regarding them as useful for monitoring achievements as the programme progressed; *“they’re helpful and just to let you kind of see what has been done” (focus group participant).* However, focus group participants highlighted that learning was shared to a lesser extent with other areas outside of Inverclyde than would have been possible without the Covid-19 pandemic; *"it's about the extent to which services had to be focused on. Other areas couldn't afford the time and luxury of being able to go and look at a really interesting piece of work that was happening in one area… the focus was elsewhere" (focus group participant).*

Additionally, deep dive interviews highlighted the challenges that Covid-19 has had on data analysis and activity trends. For example, *“even if you had the best dataset before and after [Covid-19] you wouldn't be able to pick out the effect of the project” (thematic interview).* Going forward, some focus group participants suggested there should be a renewed focus on accessing third sector data (to demonstrate the impacts arising from these activities), as well as dementia prescriptions (including both pharmacological prescriptions and social prescriptions for non-pharmacological interventions) and the number of unpaid carers.

5. THEMATIC DEEP DIVES AND WIDER THEMATIC AREAS OF INTEREST

This section outlines three deep dive case studies. The themes for these case studies were chosen via a combination of the RSM team mining interview transcripts for areas of positive change/ areas cited as making a difference, and suggestions from the Programme team. The case study selection process also took into consideration areas within the programme that would be useful to highlight or showcase/ share with other areas.

Three deep dives were subsequently chosen:

1. **The development of the Living Well with Dementia App** – due to its potential replicability in other areas of Scotland, combined with its person-centred development approach.
2. **The role of AHPs in the programme** – due to the positive multidisciplinary approach adopted in Inverclyde.
3. **Sustainability** - due to an interest in how the programme is ensuring that its legacy is being considered.

This section also includes wider thematic areas of interest.

This section is evidenced by qualitative engagement, including:

- five follow-up interviews to deep dive into specific thematic areas; and
- eight reflective focus groups, with operational delivery groups (x3), specialist and lived experience groups (x3) and steering group members (x2).

5.1 Deep dive case studies

Development of the Living Well with Dementia App

The app is designed to support people diagnosed with dementia at an early stage to remain independent for as long as possible.

Features of the app include access to information about local services, a self- reporting well-being tracker and personal information through a "getting to know me" (eg. religious beliefs, medication, likes and dislikes)[38]. The information contained in the app can be saved and shared with health professionals, meaning that "*they immediately get that overview of who the person is and what matters to them and they are better able then to really offer person centred care and support to that individual" (thematic interview).*

The app will enable people with dementia and their families/ carers to understand their condition and the support services available to them. As a result, the development team anticipate that once live, the app will be helpful for preparing individuals for living with dementia and the changes that their advancing condition will bring.

Development was a collaborative effort from the app team, including those with lived experience, the Knowledge Services team at NHS Greater Glasgow and Clyde, Alzheimer Scotland, Digital Health & Care Innovation Centre and Healthcare Improvement Scotland. Collaboration between partners gave a sense of shared purpose around the app's development: *"The great majority of the group members came along regularly to all the meetings were very engaged and took part in contributing content, giving feedback, etc. So, it was clear, they really saw this as a valuable development and one that they were committed to and to making work" (thematic interview).*

Those with lived experience were involved in the app development and were actively consulted at all stages. However, due to the Covid-19 pandemic it was not possible to engage those with lived experience to the level that was originally planned. Some suggested that the app would have benefitted from greater input from those with lived experiences. However, *"under the circumstances, the [development] group did really well… the strategy was always to bring service users in early on" (thematic interview).*

Those involved in app development highlighted that people living with dementia will have further opportunity to provide feedback during piloting. There are plans to pilot the app with a small group of staff and people living with dementia in late July/ August 2022, the results will be reviewed in September 2022. Roll out across Inverclyde will follow, with potential expansion across other HSPCs as the app has *"the potential for scaling".* It was noted that the app technology is flexible enough to allow other HSCPs to tailor the content to local people living with dementia in their area*; "other health and social care partnerships could have their own localised versions of the same thing. So, the same wellbeing diary and getting to know me, but different local support and service information" (thematic interview).*

Going forward it was recommended that an implementation and support plan for the app should be developed for the Inverclyde area, which could then be shared with other areas. In addition, support will be required to encourage staff to use the app as part of their consultations with those diagnosed with dementia as *"Just having an app up there on the app stores or on the web is not sufficient in itself to get it used and have an impact….you really have to work with the staff who are going to promote it." (Thematic interview).*

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[38] Alzheimer Scotland (2015) *Getting to Know Me,* Available at: https://www.alzscot.org/our-work/dementia-support/information-sheets/getting-to-know-me

The role of AHPs in the programme

Through the programme, the Inverclyde team have been able to add additional services to the Allied Health Professional Pathway; *"through the project we've been able to advance this pathway by adding other components to it" (focus group participant).*

Allied health professionals (AHPs) are professionally autonomous practitioners who provide a range of diagnostic, technical, therapeutic, and support services. Their focus is on prevention and improvement of health and wellbeing to maximise quality of life for individuals. AHP involvement in the Dementia Care Co-ordination Programme was led by Occupational Therapists.

AHP involvement has been *“threaded through the whole project purposefully” (thematic interview)*. Throughout the programme there was AHP representation on the steering group and operational group. The AHP team also contributed to programme learning sessions.

AHPs have implemented a number of occupational therapy interventions, including the home-based memory rehab. The intervention was cited as being particularly useful for those undergoing assessment for diagnosis or where a mild cognitive impairment has been observed, however, the support remains available once a diagnosis has been confirmed. Both consultant psychiatrists and PDS link workers appropriately referred to the service; *“We've been able to work with people in their homes and provide strategies in order to compensate for any issues that they have in going about their day-to-day life . It isn’t a diagnosis of dementia but a mild cognitive impairment at that stage” (thematic interview)*. Handbooks and toolkits have been developed which provide people living with dementia with self-management tools to improve their ability to live independently for longer.

As part of the PDS pathway, the Journeying Through Dementia group ran for 8-12 weeks at a time, on a weekly basis and allowed people living with dementia to access peer support, engage in meaningful activities and remain connected to their community. Referrals to this group were co-ordinated by PDS link workers. The topics explored at the group were tailored to the individuals to maximise positive outcomes for the people living with dementia involved; *"the group themselves decide which topics they want to focus on. It is part of a post diagnostic approach, and it is about homing in the skills that people have, and how they can retain those skills, but it also looks at some of the emotional well-being as well" (thematic interview)*.

Reflective practice sessions at the Journeying Through Dementia group were referenced as being particularly beneficial for people living with dementia to understand the impact of these activities on their own wellbeing; *“it allowed them to see their progression each week rather than just having the beginning and the end. I think that was quite good for them” (thematic interview)*.

To evidence the impact of their interventions on the wellbeing and confidence of people living with dementia, the AHP team developed their own set of occupational therapy-based questions which were *"along the lines of the single quality question [for PDS]"* which they distributed both before and after each intervention; *"it goes hand in hand with all the outcome measures that we use. So that gives us evidence that people are feeling the benefit, people are saying yes, I'm coping better" (thematic interview)*. The work of the AHP team and the outcomes achieved were documented by a video, which is due to launch in the latter half of 2022; *"A video will come out and which involved service, users, carers and ourselves. It's been a landmark really" (thematic interview)*.

The AHP team have also been a driving force behind the introduction of virtual home visits within Inverclyde HSCP, which enables occupational therapists to assess the home environment via Skype/ Zoom and make recommendations without having to be physically present; *"we have developed protocols and guidance and flow charts etc in terms of decision making as to when it's appropriate to utilise a digital source [for home assessments]" (thematic interview)*. The AHP team expect the use of virtual home visits to increase in the future; *“I think that is an area which will increase for occupational therapy” (thematic interview)*.

Sustainability of the programme

All those who participated in the evaluation were positive about the impacts of the programme to date and expressed an interest in continuing to collaborate on dementia care improvements within Inverclyde.

Stakeholders highlighted that high levels of attendance at the first meeting of the Local Dementia Strategy Group (June 2022) indicated that there is an appetite for partnership working to continue; *"the first meeting was yesterday, and I think we got a good turn out there. So there's clearly a lot of people who are still keen to take the work forward (thematic interview).* This group included those who were involved in the previous Dementia Strategy Group or the Care Coordination Programme. They attributed this as a legacy of the programme, and also of the work of the Inverclyde HSCP improvement advisor:

"[the advisor] got people from across Inverclyde to make good connections. They knew who to contact, who to get connected, who to get involved and therefore [they] have left lasting connections..." (thematic interview).

Through this Group, beneficial aspects of the programme (such as the Dementia Friendly Community and the app roll-out) can continue to progress. There was also widespread agreement that certain workstreams (eg. PDS and Dementia Friendly Inverclyde) should continue in the future, as these were regarded as particularly beneficial.
Some cautioned that there may be a pause in the initiation of new activities before the new dementia strategy is introduced: *"I feel I don't want to do too much work on an old strategy when we know that there's a new one coming and would be better, you know, having a fresh focus on the new strategy when it comes" (thematic interview).*

From a data perspective, there are continued plans for Scottish Government over the next 12 months (as a minimum) to provide continued analytical support in reference to the data to be collected within the Dementia Register and the Measurement and Performance Framework. To ensure that quantitative measures are of sufficient quality to be able to inform service delivery, longer-term provision of these capabilities will need to be considered.

To ensure future sustainability, stakeholders suggested that this will require building on existing:

- Strong leadership
- Partnership working
- Defined terms of reference
- Continued use of meeting briefs and action logs to provide clarity
- Coordinated approach to staff training
- Continued investment (either at a Scottish Government or a local level) in the collation of data and refinement of dementia measures

5.2 Wider thematic areas of interest

5.2.1 Collaboration

Collaboration was a key theme emerging from all qualitative interviews. Strategic stakeholders outlined how the Programme built upon an existing culture of collaboration within Inverclyde; *"the culture in Inverclyde is inclusive, and positive" (strategic stakeholder).*

Regular stakeholder meetings were regarded as positive for linking with system partners and sharing knowledge about available resources; *"I think the meetings just kept dementia as a topic and at the forefront and it in meeting with so many different professionals" (focus group* *participant)*. Having additional resource available from Healthcare Improvement Scotland was positive in supporting programme activities.

For AHPs, case review meetings (such as the Advanced Dementia Specialist Forum meetings) were useful for sharing expertise on referrals and complex service user cases, amongst relevant staff members *"there was a real learning in [those meetings] and thinking as a whole community of how we could have done that better" (focus group participant).*

5.2.2 Covid-19

During inception, the Inverclyde team used the 12 Critical Success Factors for care co-ordination to assess performance of each workstream and identify areas where the programme could make improvements. However, like other parts of the health and care system, Covid-19 had a large impact on the delivery of the programme. The programme was paused on two occasions, to ensure no additional pressure on frontline services[39].

The programme collated a snapshot view of learnings from the first wave of the Covid-19 pandemic in a short presentational report[40]. This feedback reflected on service delivery, the role of technology, the experiences of people living with dementia and the third and community sector response. The overarching theme from this learning paper relates to the resilience and the agility of the programme to reactivate following a six month pause at the beginning of the pandemic. Stakeholders referenced that there was local recognition amongst leadership as to the importance of the programme plus a commitment from staff to keep going, recognising what people with dementia and their families/carers had been going through during the pandemic.

Figure 13: Summary of key findings Covid-19 pandemic report[41]

Service delivery: Changes to operating procedures in response to the first wave were made, with those with critical and substantial needs being prioritised. Non-essential face- to- face support was suspended. Resulting in increased waiting times for non-essential services.

Family/carers experience: The Inverclyde Dementia Reference Group experienced loneliness due to the lack of social interaction and suspension of services. The group shared coping strategies and shared experiences.

Technology: The importance of the role of technology in service delivery through telephone and online platforms, enabling staff and service users to remain connected.

Third sector and community response: The response from the third and community sectors was significant during the initial period. The Inverclyde Community Action Response Group was set up by local campaigners.

Overall, the evaluation team were impressed by the commitment and passionate approach amongst staff and stakeholders (including the Project Team) to getting the Programme up and

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[39] The first programme pause was between March 2020 and September 2020. All services were paused during this period. The second programme pause was between January 2021 and February 2021 during which time limited activities continued in the background.

[40] Inverclyde COVID-19 case study 3 (ihub.scot)

[41] Inverclyde COVID-19 case study 3 (ihub.scot)

running again with a renewed focus following Covid-19 related pauses. This was repeatedly demonstrated throughout interviews/ focus groups by delivery staff and relevant stakeholders. Focus groups and interviews indicated the perspectives as detailed in the table below:

Figure 14: Reflections on the impact of Covid-19 on the Programme

1. There was a sense that more progress could have been achieved in the absence of Covid-19 *"if Covid hadn't have happened, we might have had a much wider piece of work completed, but it wasn't possible" (strategic stakeholder).*
2. Covid-19 had a negative impact on the diagnostic process as the diagnostic service was paused during the pandemic; *"the whole diagnostic service pretty well stalled, so people weren't getting the diagnosis of dementia" (focus group participant).*
3. New ways of working were regarded as a positive by the Programme team. For example, virtual working environments improved access to meetings, such as the Advanced Dementia Specialist Forum, for many staff members; *"I don't think it was impacted by COVID. If anything, there were more people involved than might have been" (focus group participant).*
4. However, Covid-19 compliant online and telephone services were not considered as accessible for people living with dementia *"telephone wasn't very helpful… those with dementia weren't able to concentrate via the telephone" (focus group participant).*
5. Going forward, stakeholders would like to see more in-person stakeholder events specifically for people living with dementia.

5.2.3 Digital solutions

The Programme involved the use of a number of digital solutions, including online conferencing software for staff, online/ telephone services for people living with dementia and the development of the Living Well with Dementia app. The use of digital solutions reflected a combination of the Programme's original digital aspirations (eg. the development of the app) as well as a response to the Covid-19 pandemic.

For staff, online meetings were regarded as having a positive impact on productivity; *"I think it was actually incredibly task focused. It was quite time-lined around what was going to happen each meeting, and we pretty much stuck to it" (focus group participant).* In addition, they also enabled a wider range of participants to attend, including clinicians and those outside of the Inverclyde area; *"quite often we find it difficult to get a doctor or clinicians involved, and actually to me, it was really surprising how many doctors had made that initial attendance" (focus group participant).*

During the pandemic, some previously in-person services (such as support groups, including the friendship group) became virtual. Staff reported that there were some practical challenges for people living with dementia with online engagement (eg. some people living with dementia struggled to connect to these online support groups via iPads). Staff also reported that virtual services could be less engaging than in-person services; *"The problem with the online groups is if there was an interruption to the connection or if there was a few people on and you know the* *pictures started moving around, it started to get quite confusing and trying to talk with a bit of a delay, people with dementia were then just giving up with it" (focus group participant).*

Additionally, some focus groups referenced that certain groups of people living with dementia/ carers were not accessing services as expected due to inequalities associated with the use of digital solutions; *"we do have areas of very high deprivation [within Inverclyde] …people don't have broadband…they don't have Wi-Fi, they don't have the internet" (focus group participant).* Strategic stakeholders also mentioned that it was challenging to capture Programme feedback (eg. during the development of the app) from those living with dementia via online methods. Inverclyde established a digital inclusion group to ensure that digital solutions were readily available to the population, however, focus groups felt that there would have been greater engagement if Covid-19 regulations had permitted face-to-face interaction. The Inverclyde team indicated that moving forward, service user interactions will be face-to-face where possible.

Once launched, it is hoped that one of the key digital outputs will be the Living Well with Dementia app. According to deep dive thematic interviews, this will be positive for helping individuals to self-manage, signpost to local services and to share personal records with staff (if desired) and indicates the Programme's commitment to creating a new digital solution; *"if we use something that was already there then it wouldn't have really been anything innovative … developing the app was a way of introducing something new" (thematic interview)*.

5.2.4 Facilitation through the local and national system

The Programme was facilitated locally by strong leadership (at all levels within Inverclyde), and co-ordination of services by the Inverclyde HSCP improvement advisor which was important given the range of partner organisations involved in dementia care. As one strategic stakeholder commented, *"having that dedicated person was key… otherwise it [the programme] becomes less of a priority. They're also vital for relationship building across stakeholders and partners".*

The input from Healthcare Improvement Scotland (who provided improvement support) was regarded as vital in in providing additional resource and accountability and ensuring that dementia care remained firmly on the agenda in Inverclyde.

Additionally, oversight from the Scottish Government was considered particularly important given the number of competing priorities within the health and social care system; *"having that oversight from a government perspective enabled me to have those conversations at a local level and say you know we've got a responsibility here [to continue work on the programme]" (focus group participant).*

5.2.5 Implications for the National Care Service

Stakeholders indicated that the development of the new National Care Service (NCS) would be an opportunity to improve dementia care across Scotland, however the majority of stakeholders were uncertain about the specific implications. Some considered that the key principles of the NCS were already in place in Inverclyde; *"things like human rights, putting people at the centre of care, thinking about carers… those are the main themes and some of the National Care Service and ambitions" (thematic interview).* Consequently, having these principles in place could help to streamline the transition to the NCS. In addition, building upon the early intervention work of the

Programme may prevent crisis interventions; *“potentially avoidable hospital admissions and early admission into expensive care home provision” (strategic stakeholder).*

Going forward, stakeholders suggested that:

- The critical success factors in Inverclyde should be considered, as they provide rich transferable learning;
- Co-location and cross-team working (eg. between mental health and learning disability teams) is key for sharing knowledge and understanding across services, resulting in more co-ordinated care;
- Thought should be given to greater integration of health and social care data nationally, including integrated data systems, to ensure that staff have access to the correct information; and
- Co-production with those with lived experience and their carers, to develop a set of national outcomes for Dementia and ensure that these encompass personal outcomes. Involving those with lived experience from the outset is key to designing a service that meets the needs of its users.

5.2.6 Other key findings

- Overall, focus group participants (including staff involved in delivery of the Programme and, those with lived experience and their families/ carers) and strategic stakeholders considered the care/ support services offered within the Inverclyde locality to be effective.
- The PDS pathway within Inverclyde HSCP was considered to be particularly effective by focus group participants. The implementation of the Alzheimer Scotland '5 Pillar Model of Post Diagnostic Support' was described as *"robust" (focus group participant)*.
- Additionally, the collaboration between services and systems in place within Inverclyde enabled people living with dementia to be identified and access PDS support as soon as possible following diagnosis; *"what we're doing at the front end of it, that helps get people connected sooner" (focus group participant).*
- Additional quality improvement resource both within Inverclyde HSCP and from Healthcare Improvement Scotland was considered to be a key benefit for the Programme; *"I think the fact that Inverclyde had the benefit of additional support and buy-in from people who have the time and the skill to look at a quality improvement vision [was beneficial]" (focus group participant).*
- Without the Programme, focus group participants suggested that knowledge of dementia and the local services available would not be as widespread. Accessing support would be more difficult for those with dementia and their families/ carers; *"What we know now would have been...beneficial years ago. The knowledge that I have now is so useful and helpful that I think it would have made life a bit easier"*.

6. WIDER LEARNING, EMERGING CONCLUSIONS AND FUTURE CONSIDERATIONS

This section outlines a number of wider learnings relating to the Programme, including areas which were considered to be key successes and those which were considered to be key challenges by those who were interviewed or participated in focus groups. It also sets out a series of emerging conclusions, linked to a number of key evaluation questions, based on triangulation of all evidence collated during the evaluation. Finally this chapter sets out considerations for the future – both in terms of local factors from the Inverclyde system that could be replicated elsewhere in Scotland, and also factors for other systems and the Scottish Government to consider when developing a similar programme.

6.1 Wider learning

6.1.1 Key areas of success

The table below highlights the key successes experienced by the Programme, which could be replicated in future programme rollouts.

Table 5: Programme successes

Key successes
Input from those with lived experience: Helped tailor the Programme in a meaningful way; *“The reference group did a lot of work on the leaflet, simple things like what organisations/ support services would be included and what those with dementia and their carers would want to know. The group were involved in keeping the leaflet dementia friendly” (focus group participant).*
Collaboration: Strong leadership at a number of levels within Inverclyde and partnership working were useful in identifying and overcoming any arising issues, as well as providing a better understanding of the different partner roles. Also, strong links were developed with the third sector (eg. housing associations, charities and community organisations); *“you’ve got geriatricians, you've got palliative care nurses, you've got third sector. And everybody has a coordinated vision in terms of doing what is best for the individual, their family and their carers” (focus group participant).*
Commitment to dementia care and to the Programme: Ongoing and continuous commitment from all partners, plus an *“existing and developed culture of quality improvement [within Inverclyde]" (strategic stakeholder)*.
Programme support: Well-structured programme, eg. with a Steering Group, Operational Group and various sub-groups, inclusion of regular reporting mechanisms, meeting agendas, briefs and action logs. Throughout the Programme, weekly PDS meetings, regular ADPM/ADSF meetings and progress reporting allowed those involved in the programme to proactively review the different elements and issues that arose within the Programme in a timely manner.

Learning sessions: Contributed to improved knowledge of available resources. Dementia awareness increased across all partners involved (including housing providers and the Police).
Input of the Scottish Government and Healthcare Improvement Scotland: Added gravitas, resource and accountability *“the focus from HIS was the key to keeping us to account” (strategic stakeholder)*.

6.1.2 Key areas of challenge

The table below highlight the key challenges experienced by the Programme, which may impact on any similar programme. As this was a summative evaluation, the key challenges below were identified via reflection following the end of the Programme. More detailed challenges may have been identified, particularly in the early stages of set up and implementation, if this had been a formative evaluation.

Table 6: Programme challenges

Key areas of challenge
Data collection: Low levels of data on service user outcomes, meaning that limited analysis was possible on its impacts on people living with dementia. However, it should be recognised that data collection for programmes of this nature take time to embed, and that this was further impacted by the pandemic : *“even if you had the best dataset before and after [Covid-19] you wouldn't be able to pick out the effect of the project” (thematic interview)”* National challenges also exist around limited dementia diagnosis data; *“There’s no data about, not just with the programme but across the board” (focus group participant).* Updating information and data collection categories on an on-going basis would allow for and maintain an accurate picture of the Programme.
Timescales: Developing and embedding a programme of this nature takes time, particularly in light of the programme pause due to Covid-19; *“there were a number of partners whose focus had to shift elsewhere just given the context of COVID” (focus group participant).* In addition, more time is needed to evidence all outcomes. For example, users who were diagnosed with Dementia at the outset of the programme may not yet have touched upon the full "roadmap" of services available. More time is needed to measure the change in their outcomes.
Covid-19: Led to the Programme pause and impacted on the way services could be delivered, as well as the number of people receiving a dementia diagnosis. The use of digital solutions was sometimes a challenge for people with dementia (eg. online meeting software and online support groups); *“professionals can get online for zoom meetings, but the families less so” (focus group participant).*
Changes in key personnel: Impacted upon Programme knowledge and leadership *“unfortunately, the truth is sometimes in organisations that it’s the key individuals...driving it… when…that person …move[s] on somewhere else, then it can have a real impact” (strategic stakeholder).*

6.1.3 Contributing factors for success

From the focus groups and interviews, stakeholders suggested contributing factors of success include:

Figure 15: Contributing factors for success

1. Strong leadership at various levels of the programme (including from the Inverclyde Improvement Advisor) has been instrumental in developing relationships with partners including third sector and ensuring that the programme remains on top of people’s agendas.
2. The presence of the project improvement advisor was considered as ‘critical’ to the success of the programme as they provided support across the system and staff were aware of who to go to for information.
3. Active inclusion of those with Dementia and their carers in decision making. For example, the Dementia Reference group were heavily involved in the development of the programme leaflet. The Inverclyde improvement advisor consulted regularly with the Dementia Reference Group which was a *“strong factor”* in ensuring their views were incorporated into pieces of work.
4. The ability of the programme to evidence change (eg. reduced PDS waiting lists) has helped to achieve buy-in from partners.
5. A shared vision for the direction of the programme and a willingness amongst all staff members and partners to collaborate; *“there's a general willingness and desire to work together across the board” (focus group participant)*.

6.2 Emerging conclusions

Based on evaluation activities, the following conclusions have emerged based on the overarching outcomes for the Programme:

6.2.1 Has the Programme delivered on its aims and objectives?

The Inverclyde Dementia Care Co-ordination Programme aimed to:

- Develop a model of effective care co-ordination for people with dementia and their carers from diagnosis to end of life;
- Improve care co-ordination for people with dementia and their carers;
- Develop and evaluate a model of effective care coordination for people with dementia and their carers; and
- Share learning across NHS Greater Glasgow and Clyde (NHSGGC), Scotland and further afield.

To meet the aims and objectives of the Programme, a number of key deliverables have been developed , including the Inverclyde Dementia and Support Services Leaflet, Dementia and Palliative Care Identification Tools Guide, Single Quality Question evaluation, Learning Disabilities Advanced Dementia and Care Home Needs Guidance, AHP, Housing and Dementia Framework and Living Well with Dementia App (currently being tested). A number of internal evaluations have also been undertaken to test a range of outputs and elements of the model of care co-ordination, such as the PDS Weekly Meetings and the ADSF. It was identified that the ongoing work of the Dementia Reference Group was vital in ensuring that the views of those with lived experience and their families/ carers were incorporated into the Programme.

Learnings were shared using the flash reports (including learning sessions and steering group reports), however, there was some suggestion that learning was shared to a lesser extent with NHSGGC and nationally than would have been, if it weren’t for the Covid-19 pandemic.

6.2.2 Has the Programme delivered its intended outcomes?

The Programme has four overarching outcomes, which include:

Outcome 1: A personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer.

The Inverclyde Programme **achieved** its outcome of providing personalised and human rights-based approach to care. Early intervention was regarded as key to avoiding individuals having to go into residential care earlier than expected. Greater links with the third sector (for example, housing associations, charities and community organisations), joined up working between HSCP services and tangible resources (such as the leaflet and the Access First telephone line) were considered important in enabling people to self-manage and live independently for longer.

Outcome 2: A better person experience, improved quality and better outcomes for people in the area living with dementia and their carers.

The Inverclyde Programme **partially achieved** its outcome of providing a better person experience and better outcomes for people living with dementia. Joined up care has been key in providing a quality service for those living with dementia, which has been facilitated by regular communication between system partners. Increased PDS link worker resource has contributed to reduced PDS waiting lists, meaning individuals are being referred and receiving care earlier in their condition. However, outcomes may have been greater in the absence of Covid-19, as this impacted on the number of people receiving dementia diagnoses and altered service delivery. The 5 Pillar Model of PDS is embedded within Inverclyde, however more work is needed to implement the 8 Pillar Model of Community Support and differentiate the Advanced Dementia Practice Model from other methods of palliative/ end of life care. Therefore, some of the intended outcomes may take a little longer to be realised.

A future programme evaluation will be able to determine if longer-term outcomes have been fully achieved (particularly when further evidence from people living with dementia and/or their carers is available, which proved to be a limitation within this evaluation).

Outcome 3: A more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care.

The Inverclyde Programme has **partially achieved** its outcome of providing a more integrated and co-ordinated approach. There has been a strong existing culture of integration within Inverclyde, which has been supported by an evident willingness from all system partners to work together, particularly with the third sector. High levels of collaboration were particularly positive given the context of Covid-19. However, more time to access impacts over the longer-term and the more detailed exploration of outcomes/impact would be required to fully evidence if this collaborative approach has positively impacted upon those living with dementia and their families/ carers.

A future Programme evaluation will be able to determine if longer-term outcomes have been fully achieved (particularly when further evidence from people living with dementia and/or their carers is available, which proved to be a limitation within this evaluation).

Outcome 4: Effective monitoring and measurement approaches that can adequately assess the effectiveness and quality of the 'whole system' locality approach.

The Inverclyde Programme has **partially achieved** its outcome of effective monitoring and measurement processes. Throughout the programme, there has been evidence of ongoing monitoring and measurement processes. Flash reports (including learning session and steering group reports) were helpful for staff members in monitoring achievements as the programme progressed. However, Covid-19 had an impact on data analysis and activity trends related to services (ie. reduced numbers of diagnoses, as a result of disruption to the diagnostic process and a reduction in the number of people presenting for diagnosis, have influenced the levels of service activity data). There is also limited collection of longer-term outcome measures to be able to understand how the Programme has changed the outcomes of those with dementia. However, it is acknowledged that the development of these measures may be more effective at a national level.

Further work which is ongoing on data collation (including any aspects which could be taken forward nationally) should support the achievement of this objective in the medium to longer term).

6.2.3 Has the Programme delivered on Government policy?

To help meet key commitments of the Scottish Government's Third National Dementia Strategy (2017), the Dementia Care Co-ordination Programme was established, with Inverclyde selected as the implementation site. It has been found that the Inverclyde Dementia Care Co-ordination Programme builds upon previous policy, including the National Dementia Strategy (2010)[42], the

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[42] Scottish Government (2010) *Scotland's National Dementia Strategy:* Scotland's National Dementia Strategy (wdhscp.org.uk)

National Dementia Strategy (2013),[43] Charter of Rights[44] and PANEL principles[45]. The Programme's workstreams and activities undertaken have been deemed to have helped to deliver upon these policies in a real and meaningful way.

6.3 Future considerations

The areas for consideration section capture key lessons and learnings that should be considered for the development of future programmes.

6.3.1 Key local factors from the Inverclyde system that could be replicated elsewhere in Scotland

The importance of having a dedicated project improvement advisor: this role was highlighted as having a clear link to the success of the Programme and providing central steering and consistency. It provided a clear point of contact for the whole system, which was key given the number of partners involved in Inverclyde. In addition, since this was a dedicated role, dementia care remained at the forefront of the agenda, and did not get lost in the sea of other system pressures. Some stakeholders also considered the externality of funding for this role (ie from the Scottish Government and Healthcare Improvement Scotland) as beneficial, and also added gravitas to the Programme.

Development of close links with the third sector: the Inverclyde Programme built upon existing links with the third sector (for example, housing associations, charities and community organisations) and took steps to ensure that there was real partnership working in place. For example, providing link workers with access to records (such as the EMIS system) cemented this integrated relationship, as it indicated that they were *"real partners within the team" (strategic stakeholder).* Going forward, other systems should consider undertaking a stakeholder mapping exercise, to chart the various partners within their localities. Creating an internal contact directory for all partners would also be beneficial, as it would outline each partner's role and contact details, facilitating communication.

Hosting regular Programme meetings, accompanied by briefs, minutes and action logs: Regular updates for all system partners helped to raise awareness of Programme developments within Inverclyde and enabled formative learning to occur. Regular meetings were also key to maintaining momentum, particularly post the Covid-19 Programme pauses. Going forward, given the range of stakeholders likely to be inputting into such a Programme, this systematic meeting approach should be adopted by other systems.

General programme structure: The general structure of the Programme as a whole may serve as a blueprint to support an improvement agenda in other localities (eg. the establishment of a

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[43] Scottish Government (2013) *Scotland's National Dementia Strategy (2013-2016):* Scotland's National Dementia Strategy (https://www.webarchive.org.uk/wayback/archive/3000/https://www.gov.scot/Resource/0042/00423472.pdf)

[44] Alzheimer Scotland (2009) *Charter of rights for people with Dementia and their carers' in Scotland:* Charter of Rights for People with Dementia and their Carers in Scotland (alzscot.org)

[45] Scottish Human Rights Commission, *A Human Rights Based Approach: An Introduction:* shrc_hrba_leaflet.pdf (scottishhumanrights.com)

Steering Group, Dementia Reference Group and App Development Group etc). The effectiveness of these groups was not evaluated due to the summative nature of this evaluation; however, stakeholders reinforced that effective leadership at all levels (including leadership of these groups) was key to the success observed within Inverclyde.

Consider how learnings from Inverclyde can be shared nationally: For example, at conferences with other health board areas, via the PDS Leads Network, at sector events or through the use of infographics or slide decks. Outputs of the Programme that are well-received by those living with dementia and their families/ carers (such as the leaflet and access first telephone) could be shared with other areas to adapt for their own programmes. In addition, the Inverclyde Programme has developed a minimum dataset, which could be shared more widely across other localities. Inverclyde should utilise national networks for localities with dementia programmes throughout Scotland, to collaborate and share good practice and the Programme successes identified by this evaluation. Where these networks do not exist, there may be merit in developing them.

6.3.2 Key factors for other systems and the Scottish Government to consider when developing a similar programme

Develop a Theory of Change model, which is updated on a quarterly basis to reflect programme developments: This model is useful for monitoring programme outputs and tracking those against anticipated outcomes and outputs. Having linkages within the model to specific diagnosis metrics is also important for improving data collation. It is important to ensure that there is sustained resource capacity for data collection and analysis, to support this work in the future.

Develop an outcomes framework to measure the impact of services on people with dementia and their families nationally: This will support local systems to monitor and track their progress dementia services against the outcomes of those with dementia and their families/ carers. This outcomes framework would also support local systems to evidence the impact (both short, medium and long-term) of their dementia service offer on a consistent basis and compare against other local systems across Scotland.

Create a robust data collection system and ensure there is sufficient dedicated resource to monitor data: The ability to use data in a systematic manner will enable programmes to evidence change, allowing for the ongoing assessment of progress. This will also increase stakeholder buy-in for the programme, as improvements for those living with dementia will be clearly evidenced. Having a clear vision at the start of the programme around the type of evidence required to demonstrate impact provides consistency and direction. Other systems could explore the minimum dataset that Inverclyde has produced as a guide for data collection. Having someone responsible for data collation and analysis is key for generating momentum and ensuring that it does not get overlooked amongst other system delivery pressures.

Consider incorporating formative evaluation activities into future programmes from inception: This will allow programmes to track progress over time and will capture ongoing insights from all staff (key in the event of staff moving posts). These evaluation activities will also highlight the type of data required to evidence the effectiveness and impact of the programme, helping to ensure that the most relevant data is collated. In addition, there may be merit in the evaluation capturing the experiences of people living with dementia and their families (eg.

through quarterly telephone calls rather than to formal surveys or interviews) to explore the impacts of the programme on a longitudinal basis.

Incorporating direct involvement of those with dementia and their families/ carers within a programme: As the Inverclyde Programme has illustrated, having the knowledge and input of those with lived experience is key in ensuring that any programme outputs are relevant, useful and accessible. This involvement should be secured from the outset of the programme. There may be merit in exploring where existing stakeholder engagement activities are occurring within the locality, and whether these existing forums could be incorporated into the programme, to avoid duplication and strengthen partnership working.

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