AGENDA ITEM NO: 11

Report To:	**Inverclyde Integrated Joint Board**	**Date:**	**21 March 2022**
Report By:	**Allen Stevenson Interim Chief Officer Inverclyde Health & Social Care Partnership**	**Report No:**	**IJB/19/2022/AM**
Contact Officer:	**Anne Malarkey Head of Mental Health, ADRS and Homelessness**	**Contact No:**	**715284**
Subject:	**DEMENTIA CARE CO-ORDINATION PROGRAMME UPDATE**		

1.0 PURPOSE

1.1 The purpose of this paper is to provide the Health and Social Care Committee with a progress report on the Inverclyde Dementia Care Co-ordination Programme.

2.0 SUMMARY

2.1 As part of Scotland's third national dementia strategy, Inverclyde HSCP was selected as the Dementia Care Co-ordination Programme implementation site. The Programme is supporting improvements and redesign of community based services to improve care co-ordination for people living with dementia and carers from diagnosis to end of life.

2.2 The Programme was due to end in March 2021, however during the first wave of the Covid-19 pandemic, the programme went into hibernation for 6 months. It was safely recommenced in September 2020 and, to mitigate impact from the pandemic, the Scottish Government agreed to fund the Programme for an additional year. Priorities and action plan were reviewed, taking account of what would be possible by March 2022. The Programme is now on its final 2 months and is due to end on the 31 March 2022.

2.3 Priority areas for improvement are: Ensuring a responsive and sustainable Post Diagnostic Support service; Integrated care co-ordination for people living in the moderate dementia that is aligned to Alzheimer Scotland 8 Pillar Model of Community Support and 12 Critical Success Factors for effective care co-ordination; and, Integrated care co-ordination for people living with advanced dementia at a palliative and/or end of life stage by testing Alzheimer Scotland Advanced Dementia Practice Model.

In addition the following actions are being implemented: Creating a sustainable approach to dementia workforce development; Development and testing of a self-management leaflet and app; Local implementation of the Dementia and Housing Framework; Enhancement of the Allied Health Professional contribution to an integrated and co-ordinated approach; Improvement in the completion and consistency of Anticipatory Care Planning for individuals with dementia; and, Re-establishment of Dementia Friendly and Enabled community work.

2.4 A Programme measurement plan which will measure impact of the Programme and will continue to monitor dementia related performance after the Programme finishes has been developed and agreed. The Scottish Government are in the process of commissioning an external evaluation. Plans are in place to share Programme learning across NHS GGC, Scotland and further afield, with an online webinar planned for March, 2022. End of Programme events are being organised with Inverclyde Dementia Reference Group and the Programme Steering Group. Discussions

and planning are underway to ensure the sustainability of improvements generated by the Programme beyond March 2022.

3.0 RECOMMENDATIONS

3.1 The IJB are asked to note the contents of this paper, Programme achievements, end of Programme planning in March 2022 and proposed sustainability plans beyond March 2022.

Allen Stevenson
Interim Chief Officer
Inverclyde HSCP

4.0 BACKGROUND

4.1 As part of Scotland's third National dementia strategy, Inverclyde HSCP was selected as the Dementia Care Co-ordination Programme implementation site. The Programme is supporting improvements and redesign of community based services to improve the experience, safety and co-ordination of care, services and support for people living with dementia from diagnosis to end of life. The emphasis is to support people to stay well at home or in a homely setting for as long as possible. Taking a whole systems and pathway approach from diagnosis to end of life, by March 2022, the programme aims to:

- 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
- Share learning across NHSGGC, Scotland and further afield.

4.2 Healthcare Improvement Scotland (HIS) are the National lead for the Programme on behalf of the Scottish Government. Funding associated with the Programme has allowed Inverclyde HSCP to recruit an Improvement Advisor to lead and co-ordinate the Programme and work with national and local stakeholders.

4.3 The Programme has actively involved stakeholders throughout. 92 stakeholders attended the launch event in September 2019, including people living with dementia, carers and representatives from local and national organisations. Priority areas were identified at the event and informed the overall Programme action plan. Shared learning, progress updates, improvement ideas and action planning have been generated through five Learning Sessions.

Arrangements were agreed to involve Inverclyde Dementia Reference Group (DRG). The DRG have been instrumental in informing and supporting key areas of work, e.g. participated in local stakeholder engagement work commissioned by HIS; development of a self-management leaflet; a single quality question for the Post Diagnostic Support service; shared their experiences during the first wave of the pandemic, which was used to inform National policy and; supporting the Programme evaluation with DRG membership included on the Programme Evaluation Project Team. Members of the DRG and others with lived experience of dementia or caring for someone with dementia have informed the development of the Living Well with Dementia app.

4.4 The Programme was due to end in March 2021, however during the first wave of the Covid-19 pandemic, the programme went into hibernation for 6 months to ensure no additional pressure on frontline services. The programme was safely 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 priorities and action plan were reviewed following recommencement, taking account of what was achievable until March 2022. Agreed priorities are listed in table 1:

Table 1: Dementia Care Co-ordination Programme Priorities February 21 to March 22

Actions: Dementia Pathway	**Actions: Cross Pathway**
Care co-ordination for people newly diagnosed with dementia, ensuring a responsive and sustainable Post Diagnostic Support service.	- Workforce Development - Clearer roles and responsibilities - Clearer service pathways including GP practices - Self- management leaflet and app - Dementia and Housing - Enhance the Allied Health Professional contribution to an integrated and co-ordinated approach - Anticipatory Care Planning and dementia - Dementia Friendly and Enabled community (aligned to Programme) - Measurement plan and evaluation
Care co-ordination for people living with moderate dementia. This will be aligned to the 8 Pillars Model of Community Support and 12 Critical Success Factors for effective care co-ordination.	
Care co-ordination for people living with advanced dementia at a palliative and or end of life stage by testing Alzheimer Scotland Advanced Dementia Practice Model.	

4.5 **Post diagnostic support (PDS) - a sustainable model**

Everyone newly diagnosed with dementia is entitled to receive a minimum of one year's post-diagnostic support, co-ordinated by a named Link Worker and have a person-centred support plan in place. This is centred on Alzheimer Scotland 5 Pillars Model of Post Diagnostic Support.

There is a PDS Local Delivery Plan (LDP) Standard which is reported in two parts:

1. The percentage of people estimated to be newly diagnosed with dementia who were referred for post diagnostic support – this is reported Scotland wide and by Health Board area.
2. The percentage of people referred who received a minimum of one year's support – this is reported Scotland wide, by Health Board and HSCP.

Data is exported to Public Health Scotland (PHS) from NHS GGC collectively. Management Information Reports detailing performance against the Dementia Post-Diagnostic Support LDP Standard are provided by PHS quarterly to each HSCP.

LDP Standard Performance: The percentage of people estimated to be newly diagnosed with dementia who were referred for post diagnostic support.

This part of the LDP standard requires the actual numbers diagnosed and referred for PDS as a percentage of the estimated incidence. Table 2 presents the proportion of people estimated to be newly diagnosed with dementia who were referred for PDS up to 31 March 2021. At the time of this report, 1 April 2016 to 31 March 2020, referral data is complete and 2020/21 is provisional. Less than half of the estimated projected numbers are diagnosed and referred to PDS across Scotland and NHS GGC. Data for 2020/21 has been impacted by the Covid-19 pandemic as there was a significant reduction in numbers diagnosed across Scotland.

Table 2: Proportion of people estimated to be newly diagnosed with dementia who were referred for PDS

Year	Scotland	NHS GGC
2016/17 (complete)	44.6%	42.7%
2017/18 (complete)	43.3%	43.1%
2018/19 (complete)	44.7%	47.6%
2019/20 (complete)	41.3%	43.1%
2020/21 (provisional)	32.2%	34.3%

LDP Standard Performance: The percentage of people referred who received a minimum of one year's PDS.

This section of the Standard is reported Scotland wide, by Health Board and by HSCP. There are two elements that are required to meet the Standard:

- PDS must commence, that is first direct intervention with a PDS Practitioner or team within one year from date of diagnosis and;
- A minimum of one year PDS is recorded from first direct intervention with a PDS Practitioner or team to PDS termination or transition date.

It can take up to two years from date of dementia diagnosis to complete PDS and LDP Standard requirements. Table 3 presents the proportion of people referred who received a minimum of one year's PDS up to 31 March 2021. Data for 2016/17, 2017/18 and 2018/19 are now complete, during this time Inverclyde HSCP compliance is 68.5%, 77.4% and 57% respectively. Remaining annual reports are provisional with PDS support ongoing. Work in underway within Inverclyde to improve LDP Standard compliance through increased investment in PDS Link Worker services.

Table 3: Proportion people referred who received a minimum of one year's PDS

Year	Scotland	NHS GGC	Inverclyde
2016/17 (complete)	75.5%	66.5%	68.5%
2017/18 (complete)	73%	63.8 %	77.4%
2018/19 (complete)	74.7%	64%	57%

2019/20 (provisional)	80%	61.4%	55.5%
2020/21 (provisional)	68.7%	43.2%	35.3%**

*** at the time of this report, PDS was ongoing for 52 referrals in 2020/21*

As a result of the investment in an additional two PDS Link Worker posts there has been a significant reduction in service waiting list and waiting times. The additional Link Workers commenced in April and May, 2021. Figure 1 below demonstrates a reduction in waiting list numbers from 85 in April to 31 with 105 new referrals during this time in October and Figure 2 illustrations a reduction in waiting times from 15 to 3 months. This has been sustained.

Figure 1: Improvements in Waiting List

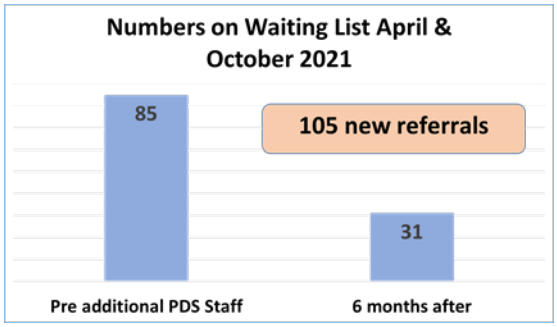
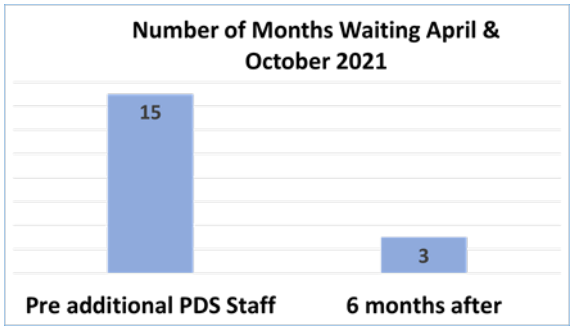


Figure 2: Improvements in Waiting Times



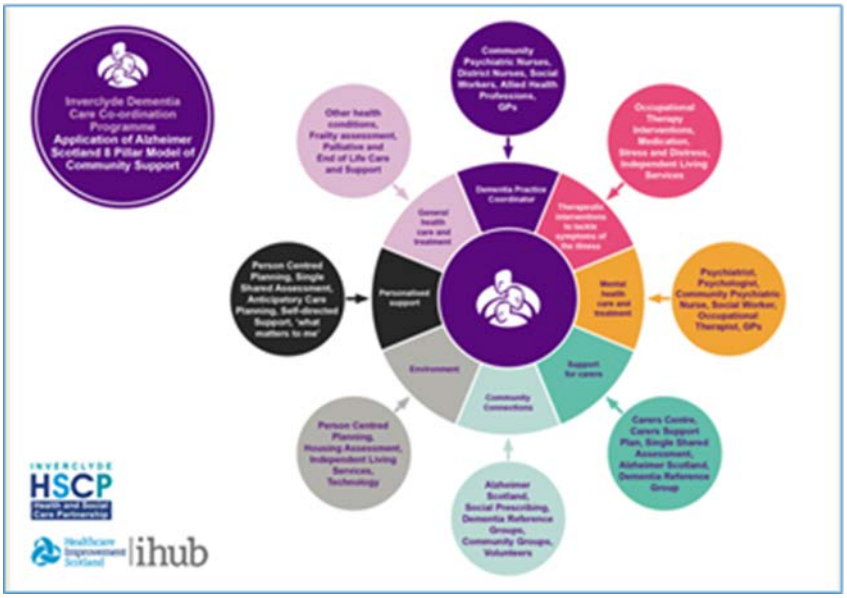
There are additional improvements ongoing including the development of a PDS service standard operating procedure; to incorporate a process of PDS service feedback and evaluation and to ensure equitable service provision that meets the requirements of the Equality Act, 2010.

4.6 **Care Co-ordination and 8 Pillar Model Community Support**

This applies to the stage of the dementia journey when people are living at home and are supported to live independently and remain connected to their community, for as long as possible, as dementia progresses. This is aligned to Alzheimer Scotland 8 Pillars Model of Community Support.

In October 2021 we hosted our 5th Programme learning session. The purpose of this was to increase awareness of services and supports for people living with dementia and carers. This was requested following feedback from participants who attended the 4th Learning Session. Plans are now underway to collate this information into a single services document that will be shared across Inverclyde. This will include a clear definition of the care co-ordination role in Inverclyde.

Figure 3: Application 8 Pillar in Inverclyde



We have also mapped existing services in Inverclyde to Alzheimer Scotland 8 Pillar Model of Community Support, (figure 3). The Model provides a coordinated and strategic framework for effective and integrated community support for people living with dementia and their carers. It addresses treatment of symptoms and aims to improve the resilience of people with dementia and their carers supporting them to live well and independently for as long as possible. It recognises that for people living with dementia to have optimal wellbeing both health and social needs required to be met.

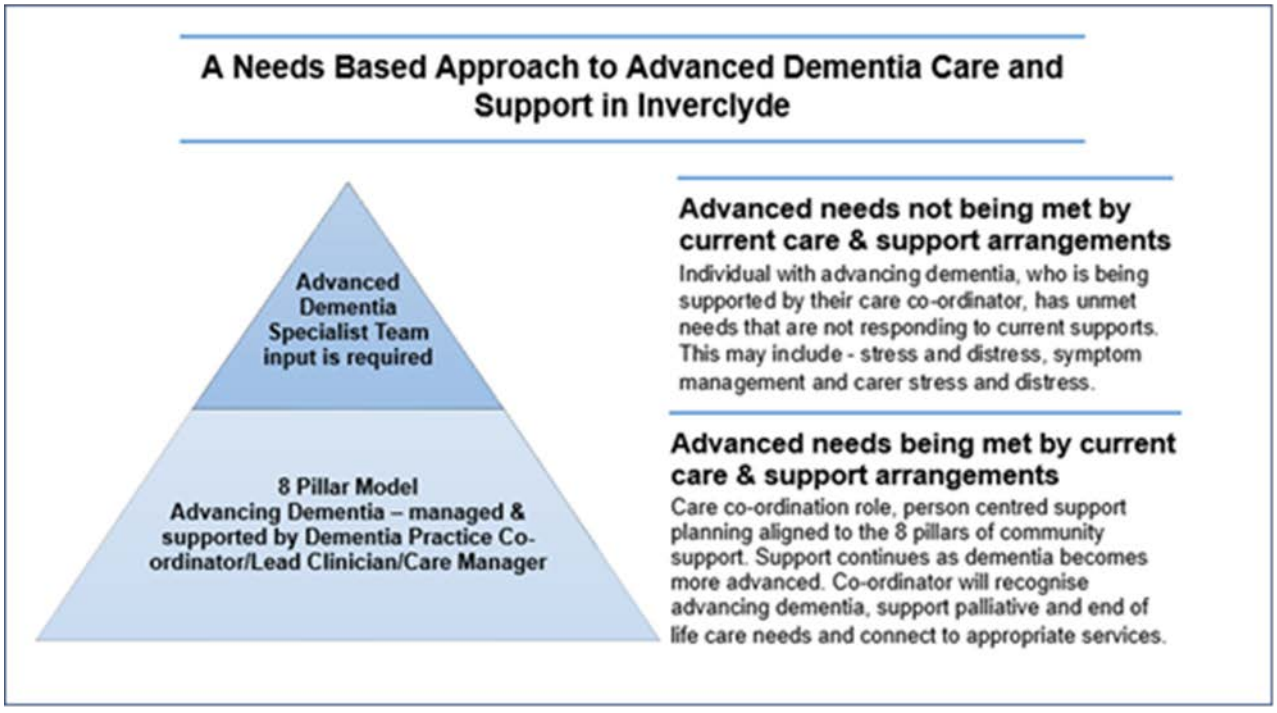
12 Critical Success Factors for Effective Care co-ordination

Work that was done elsewhere in Scotland identified 12 critical success factors that are required to ensure effective care co-ordination for people living with dementia and their carers. Inverclyde is currently collating results from the 12 critical success factors self-assessment. This will further inform local areas for improvement and action planning beyond the end of the Programme.

4.7 **Alzheimer Scotland Advanced Dementia Practice Model (ADPM)**

Testing Alzheimer Scotland ADPM is a requirement of the Programme. This Model sets out to ensure palliative and end of life (PEOL) care and support needs for people living with advanced dementia are met, including the needs of their family and or carers. A working group was established to agree how the ADPM should be implemented and tested in Inverclyde. A Needs Based Approach was agreed as a Framework to test and implement the ADPM in Inverclyde, see figure 4 below. It is recognised that the majority people living with advancing dementia will have their advancing dementia needs supported by their care co-ordinator. In order to successfully achieve this, staff need to be able to recognise if dementia is becoming more advanced. This can be difficult as the progression of dementia can be very gradual. PEOL identification tools assist in recognising changes in the stage of the illness. Where it is identified that health and social care needs are not being met, the care co-ordinator can consider if input from the Advanced Dementia Specialist Forum (ADSF) is required. In testing the ADPM we explored PEOL identification tool/s that could be used in Inverclyde and tested an Advanced Dementia Specialist Forum (ADSF) that brings together an Advanced Dementia Specialist Team.

Figure 4: Needs Based Approach to Advanced Dementia Care and Support in Inverclyde



Advanced Dementia Specialist Forum (ADSF)

The purpose of the ADSF is to ensure the best possible experience of care and support for people with advancing dementia, including their family and or carers. The Forum brings together multi-disciplinary and multi-agency expertise, including health, social care and third sector partners. The Forum aims is to facilitate discussion that leads to recommendations which support the effective and co-ordinated delivery of appropriate care and supports that takes account of the preferences of individual and their carers.

The Forum was tested over a period of 6 months from June to November 2021 and has now been evaluated. Initial reflections are that the Forum was valued and does make a difference to people with dementia and their carers. It also supports staff in managing complex situations. The multi-agency discussion and recommendations provided practical solutions to address unmet need and changed the trajectory of care and support. The Forum was particularly valued as a learning and development opportunity. There was an improved understanding of roles and

responsibilities of all health, social care and third sector services involved and the range of supports available for people living with dementia and their family or carers. Reflections from participants were that the Forum should continue, however a review of how this should be taken forward requires further consideration, in particular identifying cases for the Forum and ensuring this does not duplicate existing MDT arrangement. The final report and recommendations will be available by March 2022.

Palliative and End of Life Identification Tools

It is recognised that dementia gradually deteriorates over a longer period of time and often PEOL care and support needs are not recognised until end of life stage. It is therefore important that advancing dementia is recognised to ensure appropriate PEOL care and support is in place. A short life working group was established identify and agree an identification tool or a basket of tools that can be used in Inverclyde. Conclusions are, at the moment, that it has not been possible to determine if one tool is preferable to others. Choice of tool depends on the practitioner group, the setting and the purpose for using the tool. For example prognostication, identification of symptoms and concerns, early warning, rate of change, phase of illness and/or function is required. At this stage, Inverclyde is awaiting recommendations from the forthcoming SIGN guidelines. The identification of PEOL care and support needs will form part of local dementia workforce development plans.

Care Home Placement of Person with Learning Disability and Advanced Dementia

A need was identified by Inverclyde Community Learning Disability Team relating to the care home placement of an individual with a learning disability and advanced dementia. A short life working group was established involving local and national partners. The group has agreed to draft a guidance document for staff to support people with a learning disability and advancing dementia moving to move into a care home. It is anticipated the document will be completed by March 2022.

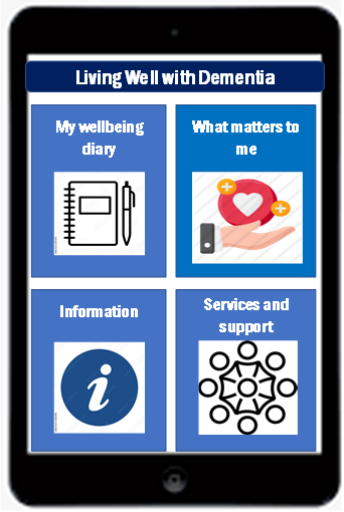
4.8 **Workforce Development**

The ambition for Inverclyde is to have a sustainable dementia workforce training and development plan in place. The Programme aims to ensure the workforce of Inverclyde, who support people living with dementia and their carers, have the appropriate knowledge and skills to support them to live well and live independently for as long as possible within their own community throughout their dementia journey. This plan will include health, social care, third sector, community groups, volunteers, housing and care home staff. A Dementia Training Co-ordinator has now been recruited and commences in January 2022. A dementia related workforce development plan will be agreed for Inverclyde.

4.9 **Dementia Friendly and Enabled Inverclyde**

Your Voice have been appointed to implement Dementia Friendly and Enabled Programme across Inverclyde. A dementia friendly community relates to relationships and inclusion within the community and a dementia enabled community is a physical environment that is adjusted to make life easier and places more accessible for people living with dementia. The Dementia Friendly and Enabled initiative commenced in October, 2021 for a period of 18 months. A progress report, will be presented to the Mental Health Programme Board in March 2022.

4.10 **Living Well With Dementia App**



A requirement of the Programme is to explore the use of digital solutions to transform services. This aims to support people living with dementia to live well and independently for as long as possible. A short life working group was established to develop the app and content. The app's development has been informed by people living with dementia and carers. Five sections have been agreed, they are:

- My wellbeing diary - to record how the user feels in a way that that can be measured over time, can be shared and links to support if required;
- What matters to me section, to record information about the user and their life story;
- A further information section;
- A services and support section;
- A section for carers will be included

We are now in the final stages of development and drafting content. It is anticipated the app will be ready for testing by the end of March 2022.

4.11 **Supports and Services Leaflet**

Plans are underway to evaluate the self-management leaflet with PDS Link Workers. The leaflet, provides information about services and supports for people living with dementia and carers and is now available. Paper copies can be obtained by calling Crown House on 01475 558000 or can be downloaded here Dementia Friendly Inverclyde - Inverclyde Council

4.12 **Dementia and Housing**

Discussions are underway to explore local implementation of the Housing and Dementia Framework. The Framework provides the tools for the housing sector to build on existing good practice and help people living with dementia, their families and carers to live in homes which have enabling environments and help them achieve the outcomes that matter most to them. Dementia awareness training, delivered by Alzheimer Scotland Dementia Advisor, is planned within local sheltered housing. Training is planned for PDS Link Workers to carry out early housing discussions.

4.13 **Allied Health Professional (AHP) contribution**

AHPs have a key role in supporting people living with dementia and their family and or carers.

Progress has been made in exploring and enhancing the AHP contribution to an integrated and co-ordinated approach as outlined in the Alzheimer Scotland AHP framework; Connecting People, Connecting Support. Occupational Therapy interventions such as Cognitive Stimulation Therapy, Journey Through Dementia and Home Based Memory Rehabilitation, are currently being delivered and evaluated in Inverclyde.

4.14 **Anticipatory Care Planning (ACP)**

There is currently improvement work in progress across Inverclyde relating to Anticipatory Care Planning. Part of this will ensure the completion and review of ACP for everyone with a dementia diagnosis. Planning is underway to train PDS Link Workers to complete and share elements of an ACP appropriate to their role.

4.15 **Measurement plan, Dementia Register and Evaluation**

A Programme measurement plan has been developed and agreed that will measure impact of the Programme, see section 8.1. This will become Inverclyde HSCP Dementia Measurement & Performance Framework after the Programme finishes. A recommendation of the Programme is to develop and test a Dementia Register for the population of Inverclyde. The aim of the register is understand Inverclyde's dementia population in terms of demographics and to inform planning that will meet local needs. Discussions are underway about how this will be collected and reported. The Scottish Government are in the process of commissioning an external evaluation of the whole Care Coordination Programme. An Evaluation Project Team has been established to oversee and steer the independent evaluation. It is anticipated that the evaluation will begin in March 2022 for a period of 6 months.

4.16 **Sharing Programme Learning**

A requirement of the Programme is to share learning across NHS Greater Glasgow and Clyde and more widely across Scotland. Programme updates have been provided at National events such as the National Post Diagnostic Support Leads meeting and shared through existing networks within NHS GGC. End of Programme events are being planned with Inverclyde Dementia Reference Group and the Programme Steering Group. An online webinar is being created to share learning from the Programme which will have a wider reach across Scotland and further afield.

4.17 **Sustainability**

The sustainability of improvements that have been generated by the Care Coordination Programme is a key focus of discussions within the closing months. As detailed in this report there are legacy pieces of work such as the training coordinator post and dementia friendly and enabled community initiative which will continue beyond the end of the Programme. Consideration is being given to reinstating the Inverclyde Dementia Strategy Group to continue work on the identified Programme priority areas and provide strategic direction and oversight to future developments.

5.0 IMPLICATIONS

Finance

5.1 Financial Implications:

Cost Centre	Budget Heading	Budget Years	Proposed Spend this Report £000	Virement From	Other Comments

Annually Recurring Costs/ (Savings)

Cost Centre	Budget Heading	With Effect from	Annual Net Impact £000	Virement From (If Applicable)	Other Comments
TBC – Dementia earmarked reserve					Dementia training co-ordinator - approximately £26,245.50 for salary and other costs for 18 months. Dementia Friendly and Enabled Community project - approximately £62,000 for salary and other costs for 18 months.

Legal

5.2 No implications

Human Resources

5.3 Job description and person specification for the dementia training co-ordinator position was complete, Grade agreed and position recruited.

Equalities

5.4 Has an Equality Impact Assessment been carried out?

	YES (see attached appendix)
X	NO -

How does this report address our Equality Outcomes?

Equalities Outcome	Implications
People, including individuals from the above protected characteristic groups, can access HSCP services.	None

Discrimination faced by people covered by the protected characteristics across HSCP services is reduced if not eliminated.	None
People with protected characteristics feel safe within their communities.	None
People with protected characteristics feel included in the planning and developing of services.	None
HSCP staff understand the needs of people with different protected characteristic and promote diversity in the work that they do.	None
Opportunities to support Learning Disability service users experiencing gender based violence are maximised.	None
Positive attitudes towards the resettled refugee community in Inverclyde are promoted.	None

CLINICAL OR CARE GOVERNANCE IMPLICATIONS

5.5 There are no clinical or care governance implications arising from this report.

NATIONAL WELLBEING OUTCOMES

How does this report support delivery of the National Wellbeing Outcomes?

National Wellbeing Outcome	**Implications**
People are able to look after and improve their own health and wellbeing and live in good health for longer.	None
People, including those with disabilities or long term conditions or who are frail are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community	None
People who use health and social care services have positive experiences of those services, and have their dignity respected.	None
Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.	None
Health and social care services contribute to reducing health inequalities.	None
People who provide unpaid care are supported to look after their own health and wellbeing, including reducing any negative impact of their caring role on their own health and wellbeing.	None
People using health and social care services are safe from harm.	None
People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.	None
Resources are used effectively in the provision of health and social care services.	None

6.0 DIRECTIONS

6.1

Direction Required to Council, Health Board or Both	Direction to:	
	1. No Direction Required	X
	2. Inverclyde Council	
	3. NHS Greater Glasgow & Clyde (GG&C)	
	4. Inverclyde Council and NHS GG&C	

7.0 CONSULTATIONS

7.1 Involving stakeholders has been central throughout the Programme. 92 stakeholders attended the Programme launch event in September 2019, including people living with dementia, carers and representatives from local and national organisations. Priority areas were identified and agreed and informed the overall Programme action plan. Shared learning, progress updates, improvement ideas and action planning were generated through 5 Learning Sessions.

Arrangements were agreed to involve Inverclyde Dementia Reference Group (DRG). The DRG have been instrumental in informing and supporting areas of work, e.g. participated in local stakeholder engagement work commissioned by HIS; development of a self-management leaflet; a single quality question for the Post Diagnostic Service; shared their experiences during the first wave of the pandemic, which was used to inform National policy and; supporting the Programme evaluation with DRG membership on the Programme Evaluation Project Team. Members of the DRG and others with lived experience of dementia or caring for someone with dementia have informed the development of the Living Well with Dementia app.

8.0 LIST OF BACKGROUND PAPERS

8.1 Inverclyde Dementia Care Coordination Programme Measurement Framework. (see appendix 1)

Inverclyde HSCP Dementia Measurement & Performance

Reporting Schedule	Frequency
Focus on co-ordination project evaluation/appraisal	End of project
Quality and Performance reporting	Monthly reports Quarterly meetings
Commissioning data sets	Monthly reports
Annual benchmarking of 12 CSF	Annually
Annual summary & assessment report	Annually

Monthly Reporting - PDS

Name of measure	Concept being measured and why it's important to look at this	Operational definition	Data collection
The impact of Post Diagnostic Support for people with a confirmed Dementia diagnosis.	The LDP Standard is that all people newly diagnosed with dementia receive a minimum of one year of post-diagnostic support (PDS) and have a person-centred plan in place at the end of that support period.	Monthly PDS LDP Standard report (Appendix)	Collected in the PHS LDP Standard report (Appendix)
Number/percentage of people with a Learning Disability with a dementia diagnosis	Knowledge of demographics of people with a Learning Disability with confirmed diagnosis of dementia	Numbers/percentages of people with confirmed Dementia diagnosis and known Learning Disability	Data collected by HSCP Data Analyst from Micro strategy
Number/percentages of people with a Learning Disability and confirmed dementia diagnosis receiving PDS provision	The LDP Standard is that all people newly diagnosed with dementia receive a minimum of one year of post-diagnostic support (PDS) and have a person-centred plan in place at the end of that support period.	Monthly PDS LDP Standard report	Collected in the PHS LDP Standard report (Appendix)

Appendix 1

Quarterly Reporting – OPMH Services

Name of measure	Concept being measured and why it's important to look at this	Operational definition	Data collection
The amount of time people with a confirmed Dementia diagnosis are placed on waiting lists for services (O)	It is anticipated that effective care co-ordination will reduce waiting list numbers and times	Numbers/percentages of people with a confirmed Dementia diagnosis and length of time placed on waiting lists for care co-ordination services including OPCMHT, Memory Clinic, AHP, Psychology, Psychiatry out-patients	Data collected by HSCP Data Analyst. Displayed monthly
Number/percentage of people receiving care co-ordination (O)	The numbers/percentages of people receiving care co-ordination will have increased	Numbers/percentages of people with a confirmed Dementia diagnosis in receipt of care co-ordination, 2019/2020, 2020/2021 & 2021/2022. This includes care co-ordination across all services e.g. OPCMHT, Access First, GP, District Nursing, Reablement, home care.	Needs data to be collected and linked from SWIFT, MH Dashboard and other systems. Diagnosis information recorded on EMIS. Use of outcome measures
Impact of care co-ordination for people with confirmed Dementia diagnosis (P)	Effective care co-ordination is based on the needs and values of service users, carers and communities	Collection of qualitative data and information of person experience of care co-ordination. This includes care co-ordination across all services e.g. OPCMHT, Memory Clinic, AHP, Psychology, Psychiatry out-patients, primary care, Access First, Reablement, home care, community supports.	Healthcare Experience Survey PDS Single Quality Question Case studies Learning events Other survey examples
Number/percentage of people with confirmed diagnosis of dementia receiving End of life care input (O)	The numbers/percentages of people with confirmed diagnosis of dementia receiving a form of EOLC will have increased.	Numbers/percentages of people with a confirmed Dementia diagnosis in receipt of EOLC input, 2019/2020, 2020/2021 & 2021/2022. This includes EOLC across all services e.g. OPCMHT, GP, AHP, District Nursing, home care, hospice, acute care.	Needs data to be collected and linked from SWIFT, MH Dashboard and other systems.
Impact of EOLC for people with confirmed Dementia diagnosis (P)	Compassionate EOLC is based on the needs and values of service users, carers and communities	Collection of qualitative data and information of person experience of care co-ordination. This includes EOLC across all services e.g. OPCMHT, GP, AHP, District Nursing, home care, hospice, acute care.	Advancing Dementia Practice Forum Case studies Learning events Other survey examples
The impact of the Allied Health Professionals contribution aligned with Connecting People Connecting Support in Action (O)	To measure/evidence developments in line with the CPCS 4 ambitions; enhance access, partnership and integration, skilled workforce and innovation and improvement	Collection of data and qualitative information associated with Occupational Therapy interventions. Including measures; Outcomes of QOL-AD tool Findings from Single Quality Question Findings from Occupation Based Question	Collected in Occupational Therapy performance reporting

Annual Reporting – Hospital Care

Name of measure	Concept being measured and why it's important to look at this	Operational definition	Data collection
Rate of unplanned acute inpatient admissions for patients with a dementia diagnosis. (O)	It is anticipated that effective care co-ordination would result in a reduction in unplanned admissions	The rate per 100,000 of unplanned acute inpatient admissions for patients with a dementia diagnosis, presented by month. Includes code 9 (AWI). Dementia diagnosis defined as documented in electronic patient records.	Data collected by HSCP Data Analyst and PHS LIST analyst. Displayed monthly
Rate of unplanned mental health inpatient admissions for patients with a dementia diagnosis. (O)	It is anticipated that effective care co-ordination would result in a reduction in unplanned admissions	The rate of unplanned mental health inpatient admissions, presented by month. Includes code 9 (AWI). Dementia diagnosis defined as documented in electronic patient records.	Data collected by HSCP Data Analyst and PHS LIST analyst. Displayed monthly
Rate of unplanned Geriatric Long Stay inpatient admissions for patients with a dementia diagnosis. (O)	It is anticipated that effective care co-ordination would result in a reduction in unplanned admissions	The rate of unplanned Geriatric Long Stay inpatient admissions, presented by month. Includes code 9 (AWI). Dementia diagnosis defined as documented in electronic patient records.	Data collected by HSCP Data Analyst and PHS LIST analyst. Displayed monthly
Rate of delayed discharges, and associate number of days (O)	It is anticipated that effective care co-ordination would lead to a reduction in the number of delayed discharges and the amount of time spent on delayed discharges	The rate of delayed discharges for patients with a dementia diagnosis per 100,000 population. Dementia diagnosis defined as documented in electronic patient records.	Data collected by HSCP Data Analyst and PHS LIST analyst. Displayed monthly
The numbers and length of time spent on delayed discharge for patients with a dementia diagnosis, as a % of all delayed discharges (O)	It is anticipated that effective care co-ordination would lead to a reduction in the number of delayed discharges and the amount of time spent on delayed discharges	Time spent as a delayed discharge for those with a dementia diagnosis as a percentage of total delayed discharge time (matches definition in Midlothian report)	Data collected by HSCP Data Analyst and PHS LIST analyst.
Unplanned admissions in last 3 months of life (O)	Effective care co-ordination should result in a reduction in unplanned admissions in the last 3 months of life	Numbers of people with a confirmed Dementia diagnosis admitted to in-patient facilities in last 3 months of life. Comparison with admissions without Dementia diagnosis.	PHS LIST analyst
Place of death (O)	Effective care co-ordination may result in an increase in the number of people die at home or in a homely setting	Numbers and percentages of the place of death of people with a confirmed Dementia diagnosis.	PHS LIST analyst

Dementia prevalence numbers and rates (B)	Knowledge of past trends can inform a trajectory of prevalence in the population for future service planning.	Source linkage files: persons aged 65+ with a dementia flag, derived from the diagnosis field in SMR hospital discharge data. Prescriptions: persons aged 65+ who received a drug associated with dementia (BNF 4.11) in the years 2012/13-2018/19. Source social care collection: persons aged 65+ flagged as having dementia in any of the quarterly submissions 2017/18 to 2018/19. Post diagnostic support (PDS): individuals aged 65+ diagnosed and referred for PDS in 2018/19. The dementia cohort was linked to death records to restrict membership to those who were alive at the end of 2018/19.	Data collected by HSCP Data Analyst and PHS LIST analyst.

Annual Reporting – Community Care & Care Homes

Name of measure	Concept being measured and why it's important to look at this	Operational definition	Data collection
Number of care home residents with a dementia diagnosis in calendar year	Percentage of care home residents with a confirmed diagnosis of dementia		
Number of people with dementia newly admitted to a care home within calendar year	Volume of admissions and prevalence of admissions with confirmed dementia diagnosis		
Reason for admission to care home	Common reasons/trends for need for admission to care home		
Age at care home admission with or without confirmed diagnosis of dementia	Average age of new admissions to care homes and comparison of confirmed dementia diagnosis and not		
Number of patients with a dementia diagnosis with a frailty score	Global analysis of population with confirmed dementia diagnosis and frailty scores. Links with service input.		

Number of patients with a dementia diagnosis with an Anticipatory Care Plan	Global analysis of population with confirmed dementia diagnosis and ACP. Links with service input.		
Number of patients with a dementia diagnosis with a Key Information Summary	Global analysis of population with confirmed dementia diagnosis and KIS. Links with service input.		
Number of patients with a dementia diagnosis in receipt of SDS	Global analysis of population with confirmed dementia diagnosis and SDS. Analysis of care provision and comparison with population without SDS.		
Number of patients prescribed drugs for dementia in the community, and total cost	Global analysis of population with confirmed dementia diagnosis and in receipt of pharmaceutical support. Analysis of cost and impact on service provision.		
Number of population with confirmed diagnosis of dementia in receipt of care from unpaid carer	Global analysis of population with confirmed dementia diagnosis and receiving unpaid care. Analysis of service input, impact on care co-ordination and supports.		

Appendix

Monthly Reporting - Post Diagnostic Support

Reference to Measurement plan	From PDS MicroStrategy Dashboard
Referrals to PDS	Number of referrals to PDS service
Discharges from PDS	Number of discharges from PDS service
PDS waiting list	Total numbers on PDS waiting list at end of each month
PDS waiting list	Waiting time: Median
PDS waiting list	Waiting time: 90th Percentile
PDS Caseload numbers and clients in receipt of 'model of care'	PDS Caseload total numbers
PDS Caseload numbers and clients in receipt of 'model of care'	PDS Caseload - Number receiving PDS 5 Pillars
PDS Caseload numbers and clients in receipt of 'model of care'	PDS Caseload - Number receiving PDS 8 Pillars
PDS Caseload numbers and clients in receipt of 'model of care'	PDS Caseload - Number receiving PDS ADPM
PDS Caseload numbers and clients in receipt of 'model of care'	PDS Caseload - Number PDS Not Appropriate
PDS Caseload numbers and clients in receipt of 'model of care'	PDS Caseload - Number receiving PDS - Model Yet to be determined