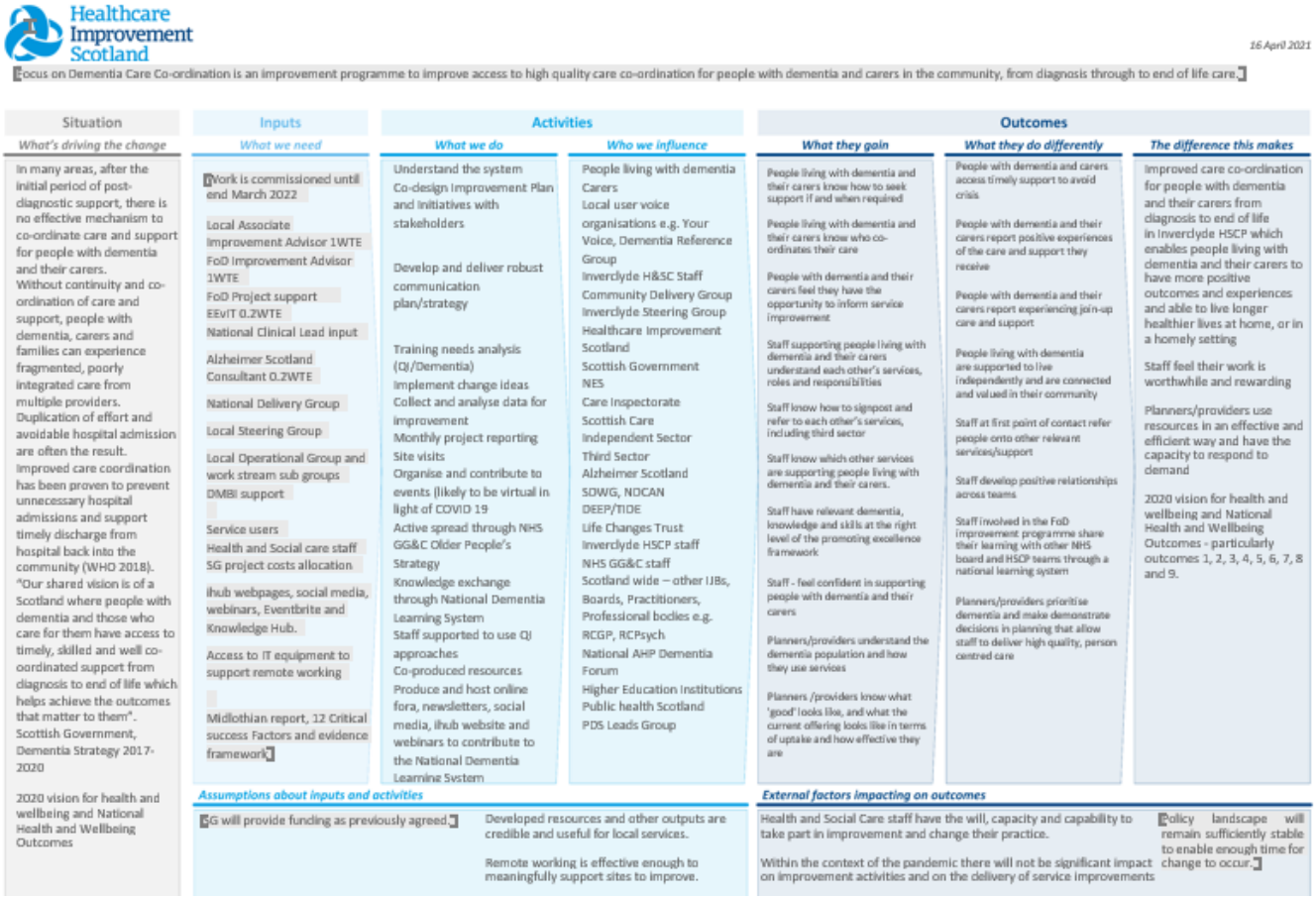
INDEPENDENT EVALUATION OF THE DEMENTIA WHOLE-SYSTEM CARE CO-ORDINATION PROGRAMME

Scottish Government – Annexes

September 2022

ANNEX 1: PROGRAMME THEORY OF CHANGE



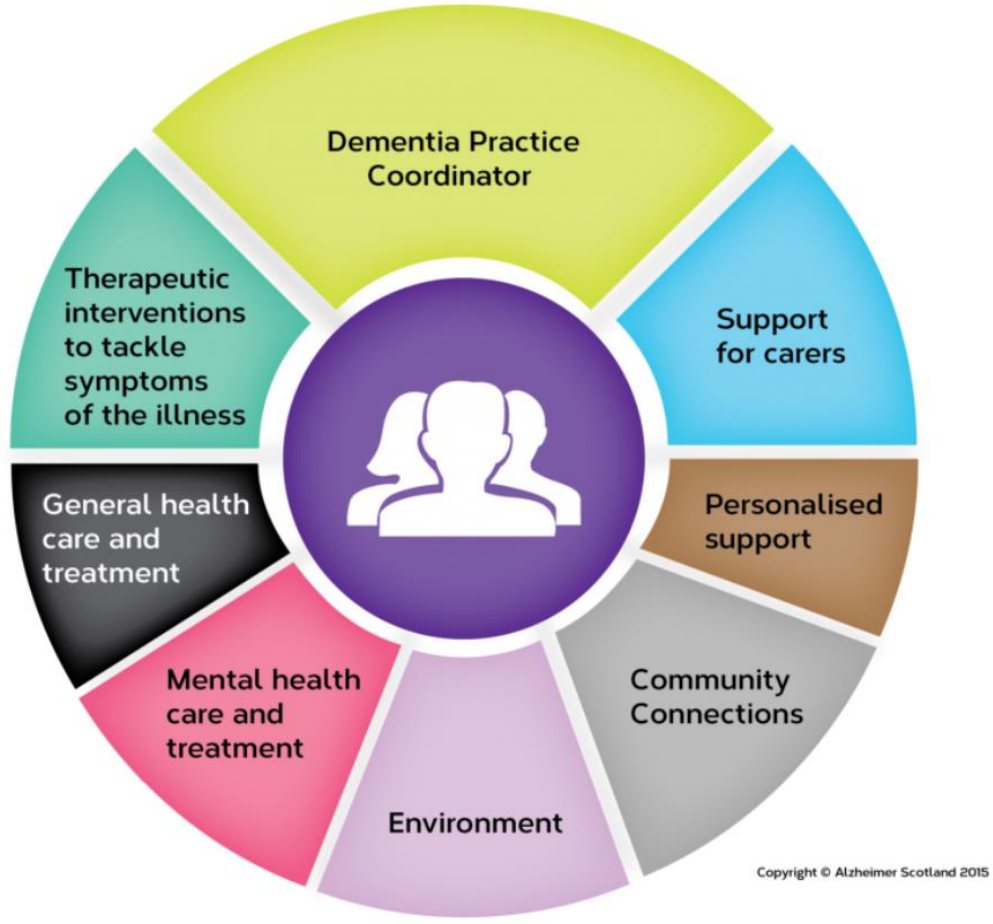
ANNEX 2: 5 PILLAR MODEL OF PDS

The Alzheimer Scotland 5 Pillar Model of Post Diagnostic Support (PDS) is a framework for those living with Dementia and their families/ carers which provides them with the tools, connections, resources and plans needed to enable them to live as well as possible with Dementia and prepare for future management of the condition[1].

[1] Alzheimer Scotland (2015) *5 Pillar Model of Post Diagnostic Support:* 5 Pillar Model of Post Diagnostic Support | Alzheimer Scotland (alzscot.org)

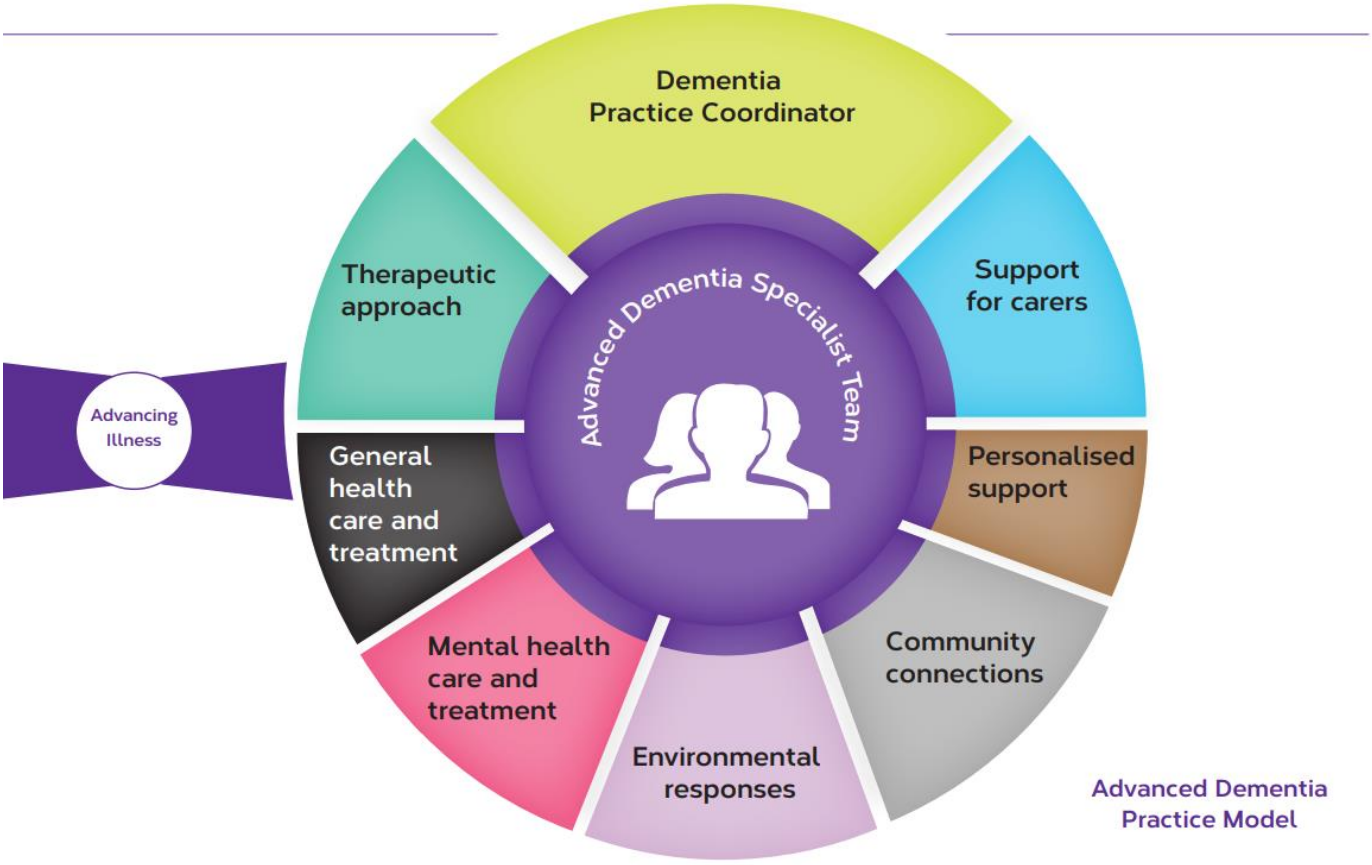
ANNEX 3: 8 PILLAR MODEL OF COMMUNITY SUPPORT

The 8 Pillar Model of Community Support builds on the 5 Pillar Model of PDS to ensure investment in early intervention is not lost. The model is an evidence-based approach which sets out how those living with Dementia can be supported to remain at home during the moderate to severe stages of their condition.



ANNEX 4: ADVANCED DEMENTIA PRACTICE MODEL

The Advanced Dementia Practice Model sets out an approach to supporting those with Advanced and End of Life Dementia.



ANNEX 5: OVERARCHING OUTCOMES MAPPED AGAINST THE THEORY OF CHANGE OUTCOMES

Overarching Planned Outcomes	Theory of Change
2,3	People living with dementia and their carers know how to seek support if and when required
2,3	People living with dementia and their carers know who co-ordinates their care
2,3	People with dementia and their carers feel they have the opportunity to inform service improvement
2,3	Staff supporting people living with dementia and their carers understand each other's services, roles and responsibilities
2,3	Staff know how to signpost and refer to each other's services including third sector
2,3	Staff know which other services are supporting people living with dementia and their carers
2,3,4	Staff have relevant dementia knowledge and skills at the right level of the promoting excellence framework
2,3	Staff feel confident in supporting people with dementia and their carers
2,3	Planners/providers understand the dementia population and how they use services
2,3,4	Planners/providers know what 'good' looks like and what the current offering looks like in terms of uptake and how effective they are
2,3	People with dementia and carers access timely support to avoid crisis
2,4	People with dementia and their carers report positive experiences of the care and support they receive
2,3,4	People with dementia and their carers report experiencing joined up care and support
1,2	People living with dementia are supported to live independently and are connected and valued in their community
3	Staff at first point of contact refer people onto other relevant services/support
3	Staff develop positive relationships across teams
3	Staff involved in the FoD improvement programme share their learning with other NHS board and HSCP teams through a national learning system
1,2	Planners/providers prioritise dementia and make demonstrate decisions in planning that allows staff to deliver high quality, person centred care

ANNEX 6: FOCUS GROUP TOPIC GUIDE

Evaluation of the Dementia Whole-System Care Co-Ordination Programme
Deep dives on thematic areas

The Scottish Government has appointed RSM UK Consulting LLP (RSM) to evaluate the effectiveness and impact of the Dementia Whole-System Care Coordination Programme being delivered within Inverclyde HSCP.

The aim of this focus group is to explore your views on the effectiveness and impact of the programme in delivering a locality-based, whole-systems approach to dementia care and services.

As part of this evaluation, we will explore with you:

- Activities and outputs of the programme
- Outcomes and impact achieved
- Reflections on what has worked well, less well and why?
- Lessons learnt and wider reflections for the future.

My name is X, and I am an evaluator from the RSM team. Thank you for agreeing to participate in this focus group. It should take around 90 minutes for our discussion.

We would like to audio record and take brief notes on our discussion. Audio recordings will be used to cross-reference our notes. Comments will not be attributed to you in our final report, and your name (and other personal identifiable information) will not be published in any way in association with the report. You are free to withdraw your data up to the point of anonymization.

Your comments will be completely anonymous and confidential, will be stored on password protected computers. The data will be kept for a minimum of six years. It will then be destroyed.

Your participation is voluntary and you are free to withdraw at any time and without any disadvantage.

Would you be comfortable for me to record our discussion?

- *[If yes]* Thank you – I am turning on the audio recorder now.
- *[If no]* Thank you – I will take brief notes as a record of the key points from our discussion.

Introduction

- To start, please could you briefly summarise:
  - Your name
  - Your role
  - Your involvement in the programme

Activities and outputs

- Can you describe the key activities, tasks or outputs which you set out to develop through the programme?

- Of those planned activities, what has been implemented to date?
    a. How, if at all, did this differ from what you set out to do?
    b. If there were changes, why was this?

- How did Covid-19 impact upon your ability to implement planned activities?

- Can you describe the different people and organisations who were involved in delivering these activities?
    a. What, if anything, worked well in those collaborative ways of working?
    b. What, if anything, could have been improved upon?
    c. Why do you say that?

- Do people with dementia and their carers have the opportunity to inform the programme and service improvement?
    a. [If yes] How?
    b. Can you please provide an example?

Achieving the planned outcomes of the programme

- From the work of the programme, to what extent do you feel that people living with dementia and their carers are empowered to self-manage and live independently for longer?
    a. Why do you say that?
    b. Can you please provide an example?

- From the work of the programme, to what extent do you feel that there is improved quality and better outcomes for people in the area living with dementia and their carers?
    a. Why do you say that?
    b. Can you please provide an example?

- From the work of the programme, to what extent do you feel that there is more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care
    a. Why do you say that?
    b. Can you please provide an example?

- How has integration and co-ordination across the system been impacted by Covid-19?

- From the work of the programme, to what extent do you feel that monitoring and measurement approaches can adequately assess the effectiveness and quality of the 'whole system' locality approach?
    a. Why do you say that?
    b. Can you please provide an example?

- Without the Dementia Whole-System Care Co-Ordination Programme, to what extent would the outcomes for those with dementia and their carers be different?

- Do you have any recommendations to improve the integration of services for those with dementia and their carers?

- Do you have any recommendations which would improve the experience of people with dementia and their carers?

Contributing factors for success

- Can you describe what you think were some of the key enablers for success of the programme?
    a. Why do you say this?

- Can you describe what you think were some of the key barriers were for the programme?
    a. How did you overcome these?

    [Prompts]
    - *People i.e the skills of those delivering the service/ training/ motivations*
    - *Context i.e the policy landscape, funding, integration of services, continuous improvement*
    - *Intervention i.e whether it's appropriate for the population, easy to use and implement*
    - *Facilitation i.e leadership to support and drive*

- From your perspective, which aspects of the programme have worked well for:
    a. People with dementia
    b. Their carers
    c. Staff members
    d. Planners/ providers

- From your perspective, which aspects have worked less well for:
    a. People with dementia
    b. Their carers
    c. Staff members
    d. Planners/ providers

Wider learning

- With hindsight, is there anything that you would have done differently in relation to the programme?

- What top tips would you give to another locality who were looking to improve on their integration of care for Dementia?

- What learning from Inverclyde do you think could shape future policy?

- Is there anything else you would like to add?

Thematic areas of learning – to be explored with appropriate groups

- Is there any learning that you would like to share from your experiences of responding to Covid-19 and how this could be embedded for the future?
- Is there any learning that you would like to share from your experiences relating to the use of digital solutions?
- Is there any learning that you would like to share from your experiences of national and local systems in their facilitation of the programme?
- From your work on the programme, are there any Implications or learning which you think could be important for the National Care Service?

ANNEX 7: STRATEGIC STAKEHOLDER TOPIC GUIDE

Evaluation of the Dementia Whole-System Care Co-Ordination Programme
Interviews with strategic stakeholders

The Scottish Government has appointed RSM UK Consulting LLP (RSM) to evaluate the effectiveness and impact of the Dementia Whole-System Care Coordination Programme being delivered within Inverclyde HSCP.

As part of this evaluation, we are hoping to interview those that we believe will hold valuable insights to understanding the landscape in which the Inverclyde Dementia programme has been implemented and the key priorities for the future. The purpose of these interviews is to explore:

- Your awareness and understanding, if at all, of the Inverclyde Dementia Care Coordination Programme;
- Your expectations of the programme;
- Areas of useful learning that could be shared from the work in Inverclyde; and,
- What you see as the vision and key priorities for Dementia Care for the future.

My name is X, and I am an evaluator from the RSM team. Thank you for agreeing to participate in this interview. It should take around 45 minutes for our discussion.

We would like to audio record and take brief notes on our discussion. Audio recordings will be used to cross-reference our notes. Comments will not be attributed to you in our final report, and your name (and other personal identifiable information) will not be published in any way in association with the report. You are free to withdraw your data up to the point of anonymization.

Your comments will be completely anonymous and confidential, will be stored on password protected computers. The data will be kept for a minimum of six years. It will then be destroyed.

Your participation is voluntary and you are free to withdraw at any time and without any disadvantage.

Would you be comfortable for me to record our discussion?

- *[If yes]* Thank you – I am turning on the audio recorder now.
- *[If no]* Thank you – I will take brief notes as a record of the key points from our discussion.

Introduction

- To start, please could you briefly summarise:
  - Your name
  - Your role
  - Your organisation

Understanding of the programme

- What is your understanding of the Dementia Care Programme in Inverclyde?

[If there is knowledge of the programme]

a. How did you first hear or become to be involved in the programme?
b. Can you describe the objectives?
c. What has been implemented?
d. Examples of outcome or impact?

Outcomes and impact of the programme

[If there is knowledge of the programme]

- From your perspective do you think the programme has improved joined up care and support for people with dementia and their carers?
    a. Why/ why not?
    b. [If yes] Please provide an example

- How might Covid-19 have impacted on the ability of the programme to provide joined up care and support?

- Do you feel that people living with dementia are supported to live independently as a result of the care/ support offered by the programme?

- Do you feel that people with dementia and their cares are connected and valued in their community as a result of the care/ support offered by the programme?

- Do you have any recommendations to improve the integration of services for those with dementia and their carers?

Expectations of the programme

[If there is knowledge of the programme]

- What were your expectations when you first learned of the programme?
    a. How, if at all, has the programme met with those expectations?
    b. Are there any areas where you feel that more could have been done?
    c. Did your expectations change throughout the Covid-19 pandemic?

Strategic alignment

[If there is knowledge of the programme]

- To what extent do you feel that the activities delivered as part of the whole-system dementia programme aligned with strategic priorities – for example Greater Glasgow and Clyde Older Peoples' Strategy?
    a. Why do you say that?
    b. What more could have been done to align the Inverclyde dementia care project to strategic priorities?

Future vision for dementia care

[Both those with knowledge and no knowledge]

- Can you describe what the future of dementia care looks like to you?
    a. How does that look different from the care provided today?
    b. How is that delivered?
    c. Who is involved in delivering the service?
    d. What are the outcomes for the person living with dementia?
    e. What are the outcomes for the system?

- What do you think are the critical success factors in achieving your vision?

Prompts linked to:

- People i.e the skills of those delivering the service/ training/ motivations
- Context i.e the policy landscape, funding, integration of services, continuous improvement
- Intervention i.e whether it's appropriate for the population, easy to use and implement
- Facilitation i.e leadership to support and drive

10. What do you think needs to happen next in the wider context to achieve this vision?

Sharing learning from the programme

[Both those with knowledge and no knowledge]

- What kind of learning would you find useful from the Inverclyde Dementia Programme?
    a. Through what mode would that learning be best communicated?

- Is there any learning that you would like to share from your experiences of responding to Covid-19 and how this could be embedded for the future?

- Is there anything else you would like to add?

ANNEX 8: DOCUMENTS/ DATA RECEIVED

Programme flash reports	PDS quality improvement framework
Focus on Dementia newsletters	Care co-ordination in the community group event information
Inverclyde Care Co-Ordination action plan	Inverclyde Covid-19 case study
Single quality question report executive summary	Inverclyde data toolkit
Data mapping framework	PDS summary data
Progress reports	Programme updates
Inverclyde Care Co-Ordination programme website stats	

ANNEX 9: EVALUATION FRAMEWORK

		Data collection approach			
Overarching Planned Outcomes	Theory of Change	Secondary data analysis	Desktop review of existing literature	Interviews with strategic stakeholders	Focus groups with key stakeholders
Story of the programme -activities and outputs					

	Understand the system		• Baseline evaluation report	• What is your understanding of the Dementia Care Programme in Inverclyde? [If there is knowledge of the programme] • How did you first hear or become to be involved in the programme? • Can you describe the objectives? • What has been implemented? • Examples of outcome or impact? • What were your expectations when you first learned of the programme? a. How, if at all, has the programme met with those expectations? b. Are there any areas where you feel that more could have been done? c. Did your expectations change throughout the Covid-19 pandemic?	• Can you describe the key activities, tasks or outputs which you set out to develop through the programme? • Of those planned activities, what has been implemented to date? a. How, if at all, did this differ from what you set out to do? b. If there were changes, why was this? • Can you describe the different people and organisations who were involved in delivering these activities? a. What, if anything, worked well in those collaborative ways of working? b. What, if anything, could have been improved upon? c. Why do you say that?

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
	Co-design improvement plan and initiatives with stakeholders		• Improvement plan • Evidence the improvement plan has been co-produced	• From your perspective do you think the programme has improved joined up care and support for people with dementia and their carers? • Why/ why not? • [If yes] Please provide an example	• Do people with dementia and their carers have the opportunity to inform the programme and service improvement? a. [If yes] How? b. Can you please provide an example?
	Develop and deliver robust communication plan/strategy		• Communications plan		
	Training needs analysis (QI/Dementia)		• Action plan		
	Implement change ideas		• Project Charter • Action plan		

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
	Collect and analyse data for improvement	• Percentage of referrals who received a minimum of one year's post-diagnostic support [LDP]	• Improvement plan	• From the work of the programme, to what extent do you feel that monitoring and measurement approaches can adequately assess the effectiveness and quality of the 'whole system' locality approach? a. Why do you say that? b. Can you please provide an example?	
	Monthly project reporting		• Monthly progress reports (examples)		
	Site visits	• Number of site visits which took place [Monthly progress reports]	• Leadership reports • Monthly progress reports		

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
	Organise and contribute to events (likely to be virtual in light of Covid-19)	• Number of events organised [Monthly progress reports] • Number of events contributed to [Monthly progress reports]	• Evaluation of events feedback • Monthly progress reports		
	Active spread through NHS GG&C Older People's Strategy		• NHS GG&C Older People's Strategy	• To what extent do you feel that the activities delivered as part of the whole-system dementia programme aligned with the Greater Glasgow and Clyde Older Peoples' Strategy? • To what extent do you agree/ disagree that the activities delivered as part of the programme had clear strategic direction?	

		Data collection approach			
Overarching Planned Outcomes	Theory of Change	Secondary data analysis	Desktop review of existing literature	Interviews with strategic stakeholders	Focus groups with key stakeholders
	Knowledge exchange through National Dementia Learning System	• Website analytics got National Dementia Learning System • Social media content/ analytics	• Case studies • Monthly progress reports • Leadership reports		
	Staff supported to use QI approaches	• Number of staff used QI approaches • Downloads of QI frameworks and self-assessment forms	• Monthly progress reports • Leadership reports		
	Co-produced resources	• Numbers of co-produced outputs [Monthly progress reports]	• Co-produced resources (examples)		

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
	Produce and host online for newsletters, social media , ihub website and webinars to contribute to the National Dementia Learning System	• Numbers of outputs on the National Dementia Learning system [Monthly progress reports]	• Outputs (examples)		
Outcomes and impact – what they gain					
2,3	People living with dementia and their carers know how to seek support if and when required	• 12 Critical success factor measures	• Case studies • Evaluation of different workstreams	• Do you feel that people living with dementia are supported to live independently as a result of the care/ support offered by the programme? • How might Covid-19 have impacted on the ability of the programme to provide joined up care and support?	• Do people with dementia and their carers have the opportunity to inform service improvement? • From the work of the programme, to what extent do you feel that people living with dementia and their carers are empowered to self-manage and live independently for longer? a. Why do you say that? b. Can you please provide an example?
2,3	People living with dementia and their carers know who co-ordinates their care	• 12 Critical success factor measures	• Case studies • Evaluation of different workstreams		

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
2,3	People with dementia and their carers feel they have the opportunity to inform service improvement		• Case studies • Evaluation of different workstreams		• From the work of the programme, to what extent do you feel that there is improved quality and better outcomes for people in the area living with dementia and their carers? a. Why do you say that? b. Can you please provide an example?
2,3	Staff supporting people living with dementia and their carers understand each other's services, roles and responsibilities	• 12 Critical success factor measures	• Case studies • Evaluation of different workstreams		• From your perspective, which aspects of the programme have worked well for: a. People with dementia b. Their carers c. Staff members d. Planners/ providers • From your perspective, which aspects have worked less well for: a. People with dementia b. Their carers c. Staff members d. Planners/ providers

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
2,3	Staff know how to signpost and refer to each other's services including third sector	• Carer referrals [TBC]	• Case studies • Evaluation of different workstreams		
2,3	Staff know which other services are supporting people living with dementia and their carers		• Case studies • Evaluation of different workstreams		
2,3,4	Staff have relevant dementia knowledge and skills at the right level of the promoting excellence framework		• Case studies • Evaluation of different workstreams		
2,3	Staff feel confident in supporting people with dementia and their carers		• Case studies • Evaluation of different workstreams		

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
2,3	Planners/providers understand the dementia population and how they use services		• Case studies • Evaluation of different workstreams		• From the work of the programme, to what extent do you feel that monitoring and measurement approaches can adequately assess the effectiveness and quality of the 'whole system' locality approach? a. Why do you say that? b. Can you please provide an example?
2,3,4	Planners/providers know what 'good' looks like and what the current offering looks like in terms of uptake and how effective they are		• Case studies • Evaluation of different workstreams		
Outcomes and impact – what they do differently					

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
2,3	People with dementia and carers access timely support to avoid crisis	• Percentage of referrals who received a minimum of one year's post-diagnostic support [LDP]	• Case studies • Evaluation of different workstreams		

2,4	People with dementia and their carers report positive experiences of the care and support they receive	• 12 Critical success factor measures	• Case studies • Evaluation of different workstreams	• Can you describe what the future of dementia care looks like to you? d. How does that look different from the care provided today? e. How is that delivered? f. Who is involved in delivering the service? g. What are the outcomes for the person living with dementia? h. What are the outcomes for the system? • What do you think are the critical success factors in achieving your vision? Prompts linked to: a. People i.e the skills of those delivering the service/ training/ motivations b. Context i.e the policy landscape, funding, integration of services, continuous improvement c. Intervention i.e whether it's appropriate for the population, easy to use and implement	• Do you have any recommendations which would improve the experience of people with dementia and their carers? • Without the Dementia Whole-System Care Co-Ordination Programme, to what extent would the outcomes for those with dementia and their carers be different? • Can you describe what you think were some of the key enablers for success of the programme? a. Why do you say this? • Can you describe what you think were some of the key barriers were for the programme? a. How did you overcome these? •

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
				d. Facilitation i.e leadership to support and drive What do you think needs to happen next in the wider context to achieve this vision?	

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
2,3,4	People with dementia and their carers report experiencing joined up care and support	• 12 Critical success factor measures	• Case studies • Evaluation of different workstreams	• From your perspective do you think the programme has improved joined up care and support for people with dementia and their carers? • Do you have any recommendations to improve the integration of services for those with dementia and their carers? • Is there any learning that you would like to share from your experiences of responding to Covid-19 and how this could be embedded for the future?	• From the work of the programme, to what extent do you feel that there is more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care? • How has integration and co-ordination across the system been impacted by Covid-19? • Do you have any recommendations to improve the integration of services for those with dementia and their carers?

		Data collection approach			
Overarching Planned Outcomes	**Theory of Change**	**Secondary data analysis**	**Desktop review of existing literature**	**Interviews with strategic stakeholders**	**Focus groups with key stakeholders**
1,2	People living with dementia are supported to live independently and are connected and valued in their community	• 12 Critical success factor measures	• Case studies • Evaluation of different workstreams	• Do you feel that people living with dementia are supported to live independently as a result of the care/ support offered by the programme? • Do you feel that people with dementia and their cares are connected and valued in their community as a result of the care/ support offered by the programme?	• From the work of the programme, to what extent do you feel that people living with dementia and their carers are empowered to self-manage and live independently for longer?
3	Staff at first point of contact refer people onto other relevant services/support		• Case studies • Evaluation of different workstreams		
3	Staff develop positive relationships across teams		• Case studies • Evaluation of different workstreams		

		Data collection approach			
Overarching Planned Outcomes	Theory of Change	Secondary data analysis	Desktop review of existing literature	Interviews with strategic stakeholders	Focus groups with key stakeholders
3	Staff involved in the FoD improvement programme share their learning with other NHS board and HSCP teams through a national learning system		• Case studies • Evaluation of different workstreams		
1,2	Planners/providers prioritise dementia and make demonstrate decisions in planning that allows staff to deliver high quality, person centred care		• Case studies • Evaluation of different workstreams		• From the work of the programme, to what extent do you feel that there is improved quality and better outcomes for people in the area living with dementia and their carers?