

Change Package for a Dementia Care Co-ordination Improvement Programme (post-diagnostic support and care co-ordination)

October 2022

Dementia Care Co-ordination Improvement Programme

The aim of this programme is to support community dementia services to improve the quality of post-diagnostic support (PDS) and integrated care co-ordination for people living with dementia and carers across Health and Social Care Partnerships in Scotland. It supports integration by facilitating communication and collaboration of community, social and health care, maximising the unique contribution of each. This Change Package has been created for the programme from the quality improvement (QI) work Focus on Dementia has already undertaken to:

- [improve PDS generally](#)
- [connect PDS to Primary Care](#), and
- [improve care-co-ordination](#).

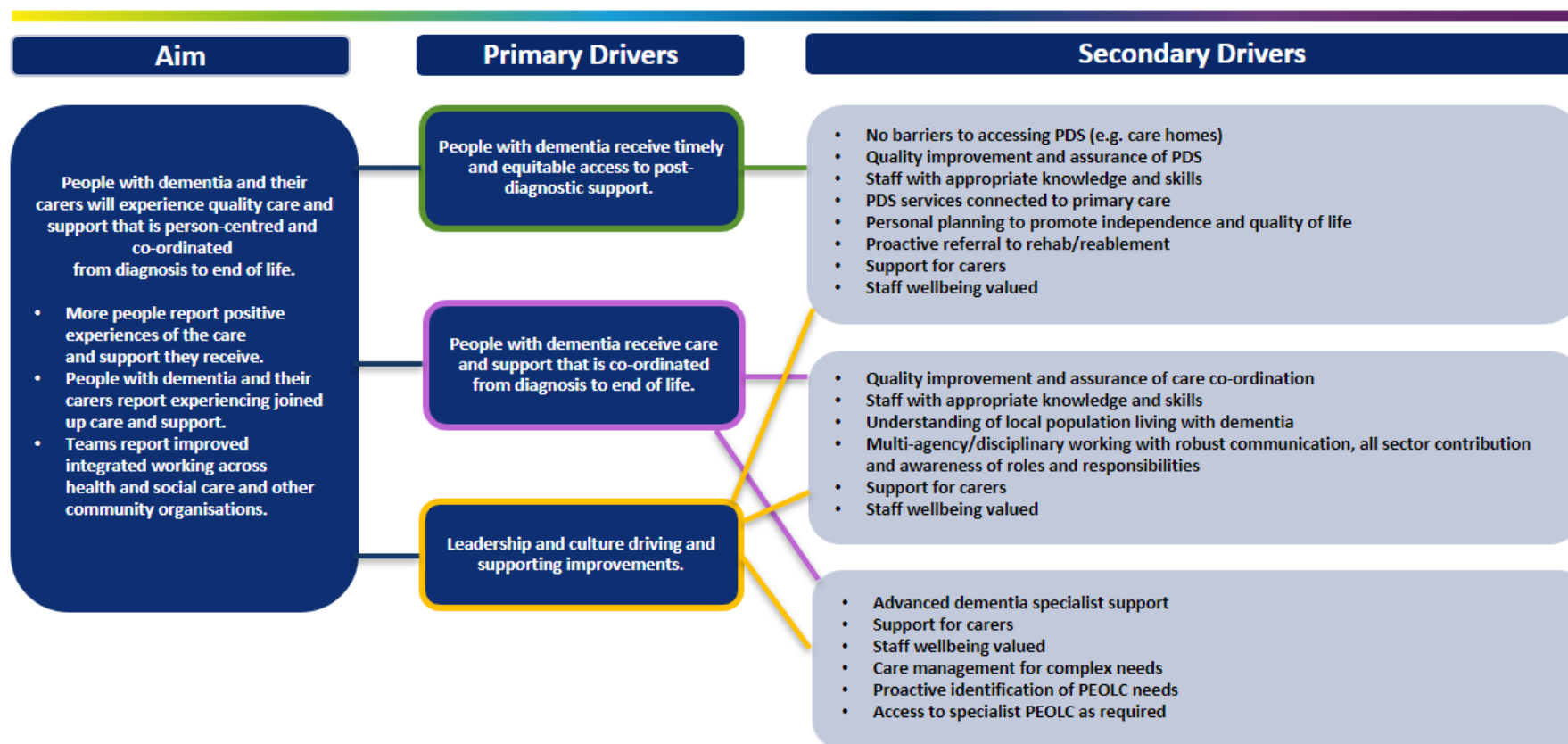
Services can use this ready-made Change Package to guide and support their improvement journey. It contains links to useful resources and tried and tested areas to consider, prioritise and implement. This guide also includes guidance on measurement.

NHS Education for Scotland's [QI Zone](#) has more information, tools and resources about measurement in quality improvement. More information on Focus on Dementia generally can be found on the [ihub website](#).

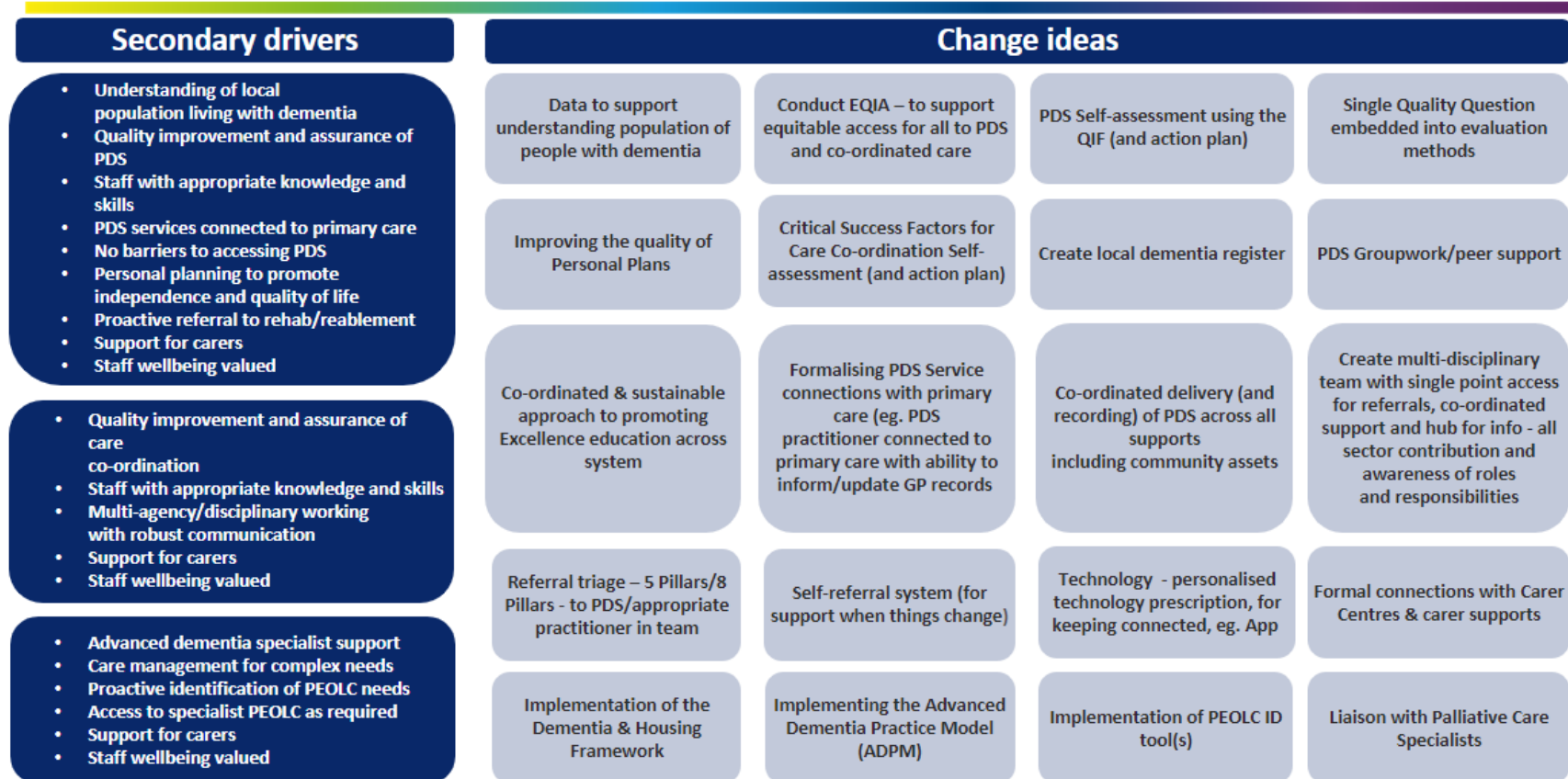
Programme Driver Diagram

The driver diagram below is based on the learning from what worked in Focus on Dementia's previous programmes. It shows the theory of change for an overall improvement programme for care co-ordination and provides some examples of change ideas. Not everything will be achievable or relevant for all services, but this diagram should be used as a motivator for improvement and for considering where the priority areas are for your service(s). The change ideas and measures are not exhaustive. We would recommend teams develop change ideas to fit their context and seek local quality improvement support, if available, in the development of additional measures as required.

Driver Diagram for the Post-diagnostic Support (PDS) and Care Co-ordination Programme



Driver Diagram for the Post-diagnostic Support (PDS) and Care Co-ordination Programme



Tools and Resources:

- NHS Healthcare Improvement Scotland. [A Quality Improvement Framework for Dementia Post-Diagnostic Support in Scotland \(2nd Ed\)](#). [online]. 2021 [cited 2022 Oct 13].
- NHS Healthcare Improvement Scotland. [Diagnosis and Post-Diagnostic Support in Primary Care](#). [online] 2021 [cited 2022 Oct 14].
- Alzheimer Scotland. [5 Pillar Model of Post Diagnostic Support](#) [online]. 2015 [cited 2022 Oct 17].
- Alzheimer Scotland. [Caring for Someone with Dementia](#). [online] 2016 [cited 2022 Oct 17].
- NHS Healthcare Improvement Scotland. [Dementia in Hospitals Improvement Toolkit](#). [online] 2021 [cited 2022 Oct 13].
- NHS Education for Scotland. [Transforming specialist dementia care in Scotland](#). [online] 2022 [cited 2022 Oct 13].
- NHS Healthcare Improvement Scotland. [Inverclyde Care Co-ordination - Inverclyde Care Co-ordination](#). [online] 2022 [cited 2022 Oct 18].
- NHS Healthcare Improvement Scotland. [Post-diagnostic dementia support and inequalities: Knowledge Map](#). [online] 2022 [cited 2022 Oct 20].

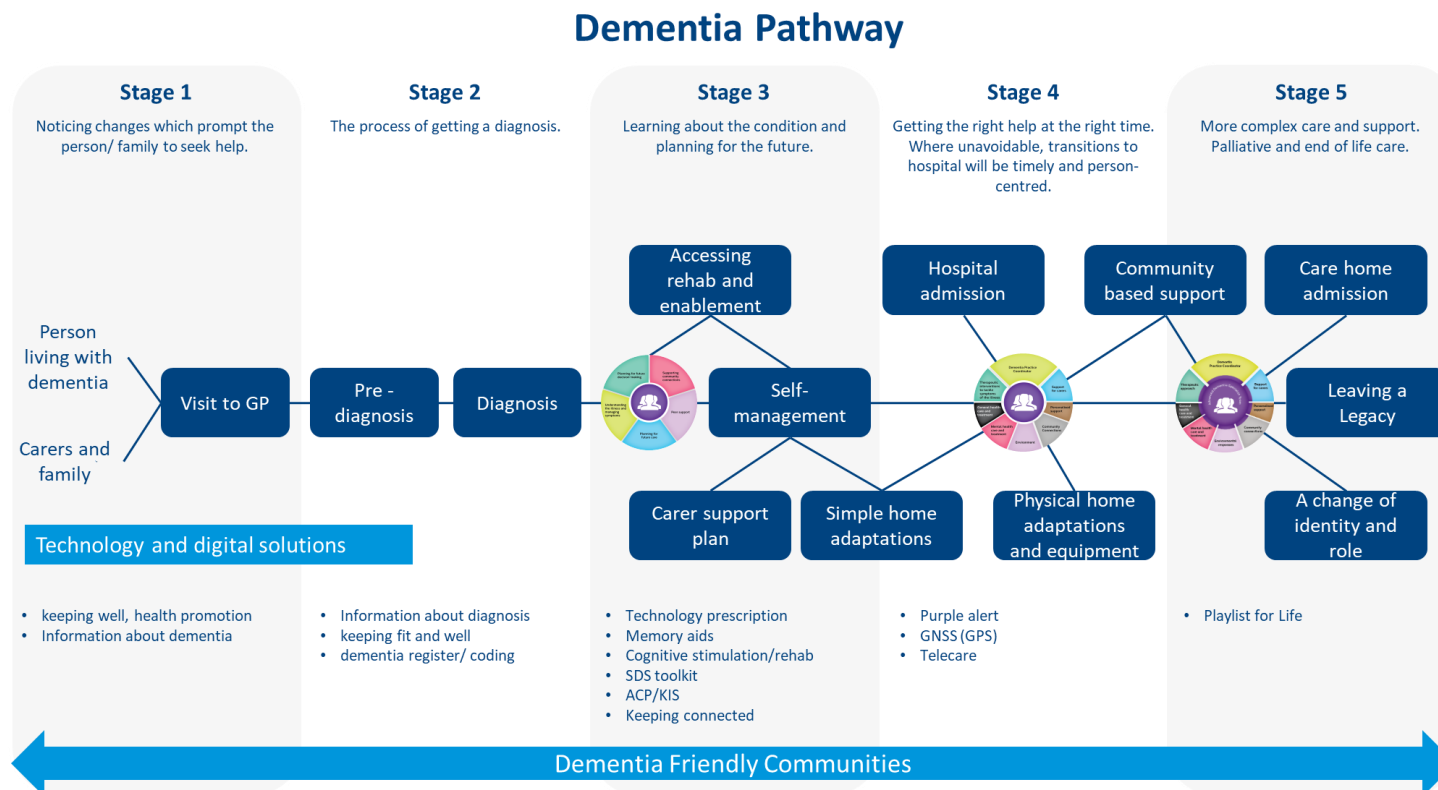
Evidence and Guidelines:

- Scottish Government. [Estimated and projected diagnosis rates for dementia in Scotland 2014-2020](#). [online] 2016 [cited 2022 Oct 13].
- NHS Healthcare Improvement Scotland & Alzheimer Scotland. [A guide to making general practice dementia friendly](#). [online] 2021 [cited 2022 Oct 13].
- NICE. [Dementia: assessment, management and support for people living with dementia and their carers](#). [online] 2018 [cited 2022 Oct 13].
- Scottish Government. [Dementia - health and social services staff: framework - Promoting Excellence 2021](#). [online] 2021 [cited 2022 Oct 17].
- Scottish Government. [National dementia strategy: 2017-2020](#) [online]. 28 Jun 2017 [cited 2022 Oct 13].
- Alzheimer Scotland & Scottish Government. [Let's get personal – personalization and dementia](#). [online]. 2010 [cited 2022 October 13].
- Scottish Government. [Standards of Care for Dementia in Scotland](#). [online] 2011 [cited 2022 Oct 13].
- Alzheimer Scotland. [Connecting People, Connecting Support in Action: An impact report on transforming the allied health professions' contribution to supporting people living with dementia in Scotland](#). [online]. 2021. [cited 2022 Oct 13].
- NHS Healthcare Improvement Scotland. [My new home: Supporting people with an intellectual/learning disability and advanced dementia moving into a care home: Guidance for Staff](#). [online] 2022 [cited 2022 Oct 13].

Taking a pathway approach

It may be useful when identifying and prioritising improvement ideas to take a pathway approach. Although everyone's journey with dementia is different and is rarely as linear as the diagram below, it does enable teams to map their services along the pathway to ascertain what is working well and where there might be areas for improvement.

Whilst the focus of this change package is post-diagnostic support (PDS), care coordination and palliative & end of life care (stages 3, 4 and 5), it is important that HSCPs are aware of how people access assessment and diagnosis within their area. Without a diagnosis, people are unable to access the care and support in stages 3, 4 and 5 in the pathway. The quarterly PDS management reports produced by Public Health Scotland provide a useful illustration of the numbers diagnosed and referred for PDS, but it will also be important to understand whether people are diagnosed through different routes, and whether all routes are linked to PDS. For examples of work to improve assessment and diagnosis please see [this webpage](#) or contact the Focus on Dementia team.



Collecting and sharing data

Measurement is an integral part of quality improvement. Being able to measure if and how your improvement efforts are making a difference is essential. Suggested measures in this document are grouped into outcome, process and balancing measures. Data should be collected frequently enough to understand if the testing and implementing of changes are leading to improvement. Data should be plotted where possible weekly (but if not, at least monthly) to give enough data points to demonstrate sustained change over time. There is also some additional information about how to carry out analysis that will help you better understand the prevalence of dementia in your population.

Any improvement project should have a small family of measures that track the progress of the project over time. These should include:

- **Outcome measures:** to tell the team whether the changes it is making are helping to achieve the stated aim. For example, “People living with dementia, carers and family members report improvements to health and social care services.”
- **Process measures:** to tell the team whether things that have to be done to achieve the desired outcomes are happening reliably. For example, “Timely offer of appropriate support following diagnosis.”
- **Balancing measures:** to check for possible consequences elsewhere in the system. For example, readmission rates.

The [Dementia in Hospitals Improvement toolkit](#) may be helpful for learning about the types of measures which are used in improvement projects. The context within which this improvement project was not the same, but some measures, and the general principles which underlie their use, may be transferable. [NHS Education for Scotland's Turas](#) platform also provides useful information on the process of selecting and developing measures for developing and undertaking measurement for improvement projects.

Teams should:

- Familiarise yourselves with the measures outlined in this document
- Decide what measures best fit with your chosen improvements
- View the data regularly as a team to ensure that changes being tested are having the desired impact

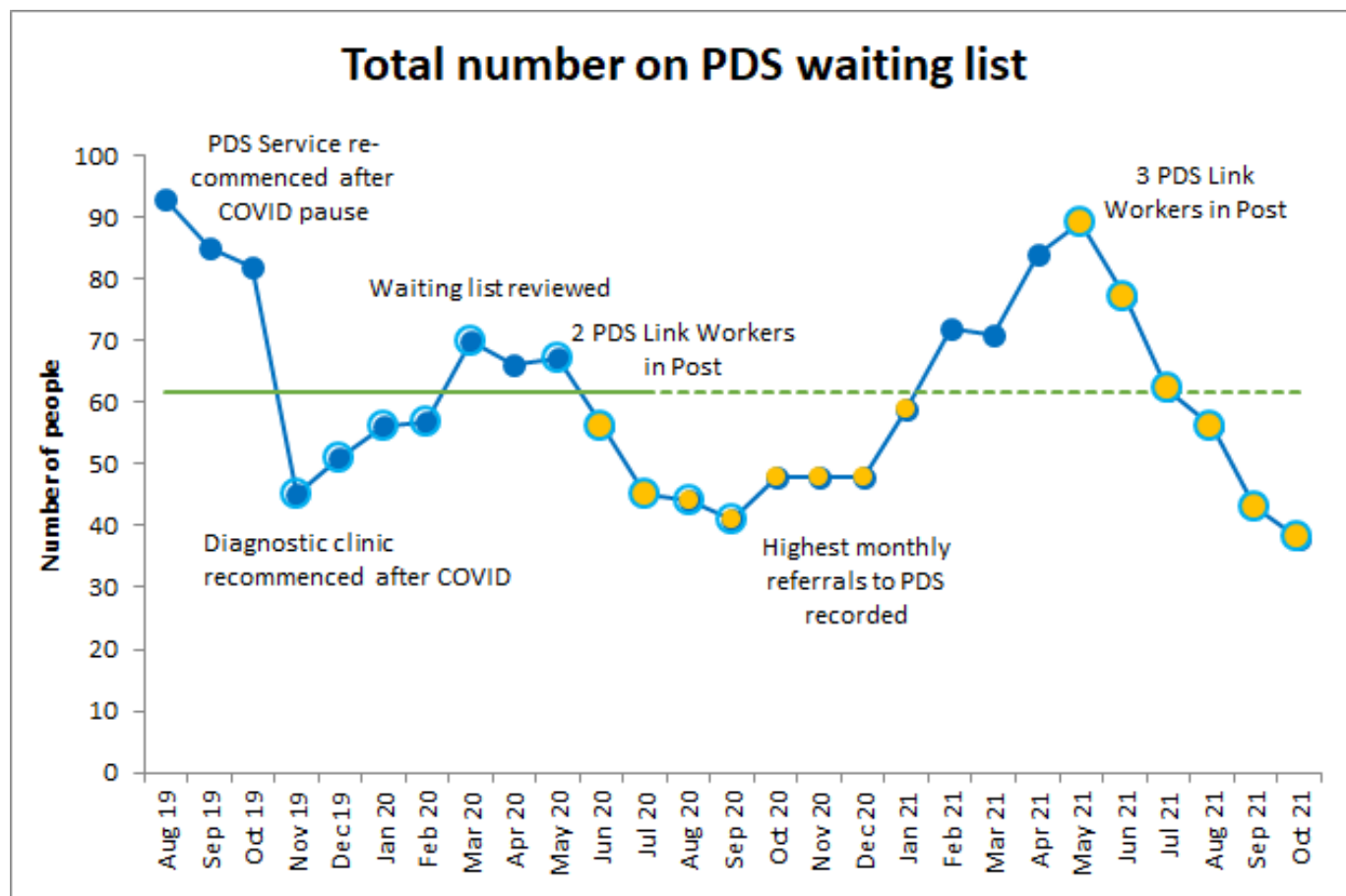
When planning your data collection, you will need to consider:

Collecting your data	Displaying your data
<ul style="list-style-type: none">• Who will collect the data?• What data will you collect?• When will you collect the data?• How will you collect/record the data?	<ul style="list-style-type: none">• What chart type you will use?• How will you share and use your data?

To learn more about measurement

The [Dementia in Hospitals Improvement toolkit](#) also contains good guidance on the development of a measurement plan. The [measurement section of NHS Education for Scotland's Turas](#) resource on the improvement journey also provides valuable information about measurement.

Run Charts (see example below) are an excellent way to present your data to help you to understand what is happening in your system. They are used to distinguish between random variation (variation that affects all processes, people and outcomes equally) and non-random variation, which could be due to the changes you have introduced. The example below shows how annotating the graph helps to illustrate what is happening to the data, positively or negatively, including the impact of improvement initiatives.



To learn more about presenting your data in a run chart:

- [Presenting your data \(NHS Education for Scotland\)](#)

Outcome measures

Outcome measures are the end results of improvement work, the measures that show you have met your aim. In this work the most important outcome is that of improved experience of the care and support the person with dementia and their carer(s) receive.

Note: Some of the longer-term measures below are dependent on having a flag to identify patients with a dementia diagnosis. Please see the Local Population section for more information on identifying patients with dementia and calculating prevalence and incidence.

People with dementia and carer experience

PDS and Care co-ordination is based on the needs and values of people with dementia, carers and communities. It is important that teams engage with people with dementia and their carers to understand their experience. This will allow teams to identify change ideas that will allow the design of person-centred services as well as ensuring any improvements are meaningful.

There are a number of ways of doing this. The Single Quality Question is a useful resource. It was specifically created to collect information on how helpful post-diagnostic support (PDS) has been to people with dementia and their carers. Although initially designed for PDS, this question can be, and has been, used successfully to evaluate other services. Find more information [here](#).

You may also be interested in:

- [Dementia in hospitals improvement toolkit: Involving relatives and carers in service improvement](#)

Staff experience

Staff wellbeing, experience and job satisfaction are key components to the success of any improvement initiative. It is important that relevant staff are fully engaged with the improvement work and any difference it has made to them is understood and captured. Measures should therefore also include staff experience.

Example of measurement plan

This table provides examples of outcome and experience measures.

Concept	Measure	Operational Definition Guidance	How to interpret	Data Collection
Experience of care and support measures	Feedback from people on the support they are receiving/have received.	Services have evaluation methods to understand the impact of improved care and support.	More people report positive experiences of the care and support they receive.	Single Quality Question (SQQ) and when to use it. Case studies Focus groups
Experience of co-ordinated care and support	Feedback from people on the support they are receiving/have received.	Services have evaluation methods to understand the perception of people with dementia and carers on how well their support and care is/has been co-ordinated following improvement activities.	People with dementia and their carers report experiencing joined up care and support.	Specific question(s) on care co-ordination. Adapt the SQQ. What would people say that illustrates this? E.g. Single point of contact or series of Qs that elicit this. Case Studies Focus Groups

Concept	Measure	Operational Definition Guidance	How to interpret	Data Collection
Health inequalities	Measurement to ensure equitable access and outcomes	All improvement activities should consider impact on equality. EQIA and data collection should be undertaken. Improvement work may target specific populations e.g. Learning Disabilities, PDS in care homes, Young Onset Dementia	Understanding who in the population is receiving diagnosis and support and if this is equitable (e.g. across the SIMD quintiles or related to specific populations) and observing where data is changing.	SQQ PDS data
Experience of delivering co-ordinated care and support (staff outcome)	Staff feedback	Services have evaluation methods to understand staff experience	Team report staff wellbeing, experience and job satisfaction. Teams report increased confidence working with people living with dementia and their carers. Teams report improved integrated working across health and social care.	Existing data capture processes such as iMatter Staff questionnaires, focus groups or interviews
Other ways of measuring care co-ordination	MDT working, Third Sector involvement, single point of access	Services have evaluation methods in place to understand care co-ordination approach	Case sampling	Last 10 Patients tool

The following 4 measures are much longer-term outcomes that may result from your improvement activities over time. These are proxy (indirect but strongly correlated) measures for care co-ordination.

Concept	Measure	Operational Definition Guidance	How to interpret	Data Collection
1. A&E Attendances	Rate of A&E Attendances	<p>Numerator: count of A&E attendances by patients with dementia.</p> <p>Denominator: total count of A&E attendances.</p> <p>The rate per 100,000 of A&E attendances for patients with a dementia diagnosis, presented by month.</p> <p>Dementia diagnosis defined as documented in electronic patient records.</p>	<p>This measure will show the rate of A&E attendances for patients with a dementia diagnosis.</p> <p>It is anticipated that effective care co-ordination would result in a reduction in A&E attendances.</p>	

Concept	Measure	Operational Definition Guidance	How to interpret	Data Collection
2. Unplanned admissions	Rate of unplanned acute inpatient admissions for patients with a dementia diagnosis.	<p>Numerator: count of unplanned admission with dementia diagnosis.</p> <p>Denominator: count of unplanned admissions or people with a dementia diagnosis</p> <p>The rate per 100,000 of unplanned acute inpatient admissions for patients with a dementia diagnosis, presented by month.</p> <p>Dementia diagnosis defined as documented in electronic patient records.</p>	It is anticipated that effective care co-ordination would result in a reduction in unplanned admissions.	

Concept	Measure	Operational Definition Guidance	How to interpret	Data Collection
3. Unplanned admissions in last 3 months of life	Rate of unplanned acute inpatient admissions in last 3 months of life for patients with a dementia diagnosis.	<p>Numerator: count of unplanned admission with dementia diagnosis and in last 3 months of life.</p> <p>Denominator: count of unplanned admission (within last 3 months?).</p> <p>Number of people with a confirmed Dementia diagnosis admitted to in-patient facilities in last 3 months of life.</p> <p>Comparison with admissions without Dementia diagnosis.</p> <p>Is denominator all admissions in last 3 months of life?</p>	Effective care co-ordination should result in a reduction in unplanned admissions in the last 3 months of life.	
4. Place of death		Numbers and percentages of the place of death of people with a confirmed Dementia diagnosis.	Effective care co-ordination may result in an increase in the number of people dying at home or in a homely setting.	

You may also be interested in:

- [Dementia in hospitals improvement toolkit: Involving staff in service improvement](#)

Process measures

Process measures are the things you are going to do to deliver the outcomes you want. They are context specific and depend upon the change ideas being tested and implemented. Teams are asked to develop their own process measures based on the change ideas they are testing locally.

NHS Education for Scotland's QI Zone has a helpful [guide to defining measures](#) and Focus on Dementia may be able to provide tailored advice and guidance on creating local process measures. If you would like advice from Focus on Dementia, please contact us at his.focusondementia@nhs.scot.

Below are some examples of process measures for PDS and Care Co-ordination. Select the ones that best align to your pathway and priorities for improvement.

Change Concepts	Example process measures
PDS	<ul style="list-style-type: none">• Number of people with a new diagnosis of dementia• Reduce waiting times for PDS• Increase the number of people accessing PDS• Increase the number of people with a personal plan• Increase Link Worker connections and communications with primary care
Personal Plans (Anticipatory Care Plans)	<ul style="list-style-type: none">• Increase the number of people (with a dementia diagnosis) with a Personal Plan• Improve the quality of Personal Plans
Care Co-ordination	<ul style="list-style-type: none">• Increase MDT working• Reduce multiple points of access• Increase engagement with the Third Sector• Increase engagement of people with dementia and carers in planning
Delayed Discharges	<ul style="list-style-type: none">• Reduce delayed discharges for people with a dementia diagnosis – POA, MDT working
Carer Support	<ul style="list-style-type: none">• Increase number/percentage of carers with carer support plans• Increase number/percentage carer centre referrals
Frailty assessment	<ul style="list-style-type: none">• Increase number/percentage of people with dementia with a frailty assessment
Staff knowledge and skills	<ul style="list-style-type: none">• Increase number/percentage of staff trained to appropriate levels of the Promoting Excellence Framework• Increase number/percentage of staff trained to appropriate levels of the Trauma Informed Practice: A Toolkit for Scotland

Balancing measures

Balancing measures check for possible consequences that your improvement activities may have elsewhere in the system.

Balancing measures will depend on the focus of your improvements and interpretation, the examples below may work better as outcome or process measures. As well as gathering data for the measures below, sites should consider any additional balancing measures based on the change ideas they are testing locally.

Concept	Example balancing measure
Health inequalities	<ul style="list-style-type: none">Interventions to improve access can either widen or narrow existing inequalities within a local population. Services that have identified a particular demographic, geographic or socioeconomic inequality as a priority for improvement could measure any of the above outcome or process measures for that group separately or construct their own targeted measure. For example, number of people from a certain population such as people with a learning disability receiving PDS.PDS publication splits referrals and receipt of 1 year support by SIMD, see data tables tab 5, and by age band, see tab 4.
Access to care and support	<ul style="list-style-type: none">Waiting times for services e.g. AHPsPDS link worker case load numbers
Impact on acute services	<ul style="list-style-type: none">Delayed dischargeGeriatric ward beds

Local Population

As mentioned above many of the outcome measures are dependent on being able to identify people with a dementia diagnosis. Understanding the *known prevalence* (people with a diagnosis of dementia known to services) within an area provides a basis for improvement activity: not just measuring change and outcomes, but also supporting services to identify and target areas for improvement. A focused piece of work may be required to understand and collate information from different sources. For example, when Inverclyde HSCP looked to understand its known prevalence, data was extracted from recording systems for Older People's Mental Health services, social care services, post-diagnostic support, prescribing, GPs, and hospitals.

For more information contact the Focus on Dementia team his.focusondementia@nhs.scot

Finally

We hope you find this Change Package useful for your Quality Improvement work. If you have any queries, or wish to give us feedback on using this package, please contact us on his.focusondementia@nhs.scot

Good luck on your improvement journey!