Healthcare Improvement Scotland

NHS Education for Scotland

care inspectorate

Person-centred approaches to reducing stress and distress for people living with dementia

Change package

January 2025

Leading quality health and care for Scotland

NHS SCOTLAND

Introduction

Welcome to the person-centred approaches to reducing stress and distress for people living with dementia change package

The aim of this change package is to support teams to improve the experience and outcomes of people living with dementia in hospital and care home settings through the implementation of person-centred approaches to prevent and support stress and distress. This change package is for all hospital and care home settings that support people living with dementia. This includes specialist dementia units, acute and community hospitals and care homes.

Why have we developed this change package?

A change package is a practical tool that can support teams during the planning of improvement activity. It can help teams to understand what part of their service needs to change to enable improvement, to identify change ideas for testing and how to capture data to evidence their impact.

This change package has been developed using learning from improvement programmes working with hospital and care home teams across Scotland and has been designed to support the implementation of the SIGN 168 guideline: Assessment, diagnosis, care and support for people with dementia and their carers*.

*In this change package 'carer' is defined as those who, "provide care and support to family members, friends, and neighbours. The people they care for may be affected by disability, physical or mental ill-health, frailty, or substance use. A carer does not need to be living with the person they care for. Anybody can become a carer at any time in their life and sometimes for more than one person at a time. Carers can be any age from young children to very elderly people." (The Carers (Scotland Act) 2016)

Contents and how to use the package

What is included in this change package?

- driver diagram
- change ideas
- examples of tools, resources, supporting evidence, and guidelines, and
- guidance to support measurement.

How to use this change package?

A Reducing Stress and Distress Self-Evaluation Tool has been developed to support teams to evaluate their current practice and identify areas for improvement relevant to their local context. It is recommended that this is completed before using this change package.

It is not expected that teams will work simultaneously on all aspects of their service. 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.

Project aim

Setting a project aim

All improvement projects should have an aim that is **S**pecific, **T**ime bound, **A**ligned to objectives and **N**umeric (STAN).

The aim for the Reducing stress and distress improvement programme:

People living with dementia have improved experience of and access to person-centred approaches to prevent and support stress and distress in hospital and care home settings by [Insert Locally Agreed Date]

Understanding what needs to change

Before starting a project, it is important for teams to understand what parts of their service need to change to ensure everyone has a shared sense of why and is focused on changes that will impact most beneficially on their system and service.

A driver diagram is a tool that visually presents a team's theory of how an improvement goal will be achieved. It articulates which parts of the system need to change, in which way and includes ideas of how to make this happen. It is used to help plan improvement projects and ensure team engagement.

Primary drivers

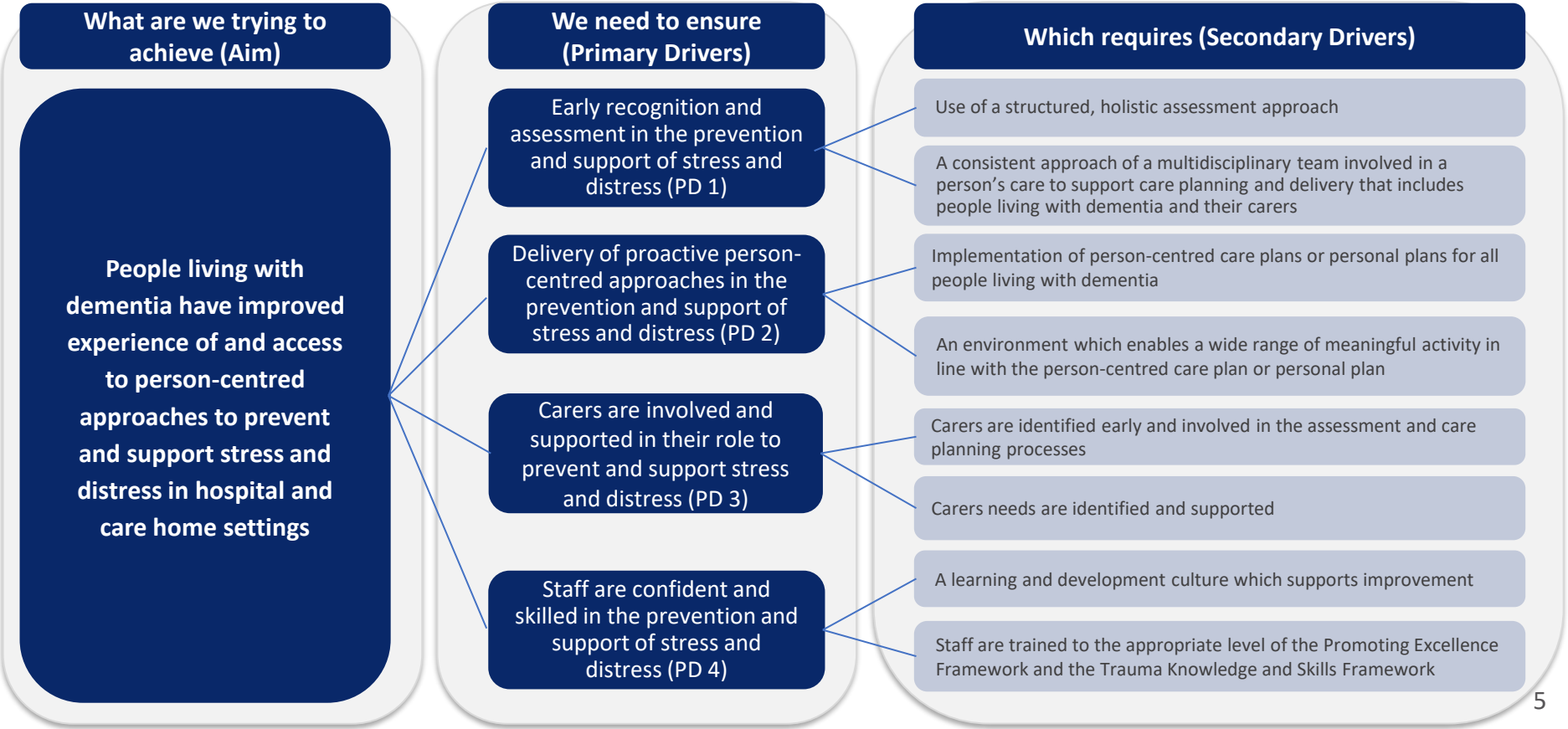
The primary drivers are the key components of the system that must change to deliver the aim. They are not listed in order of priority. The reducing stress and distress primary drivers align with the key principles outlined in the SIGN 168 guidelines.

Secondary drivers

The secondary drivers are the processes that influence the primary drivers. Changing the processes outlined in the secondary drivers should change the primary drivers and deliver the aim.

Click for more information about Driver Diagram on NHS Education for Scotland's QI Zone.

Driver Diagram: Person-centred care approaches to prevent and support stress and distress for people living with dementia



Change ideas

Change ideas

Change ideas are specific practical changes the team can make to alter the processes in their service. These ideas can be tested, and the impact measured to understand and evidence if this change leads to improvement. Project teams should select change ideas based on their understanding of their local system. A range of change ideas will need to be tested to ensure there are changes to all primary drivers.

The following pages provide some suggestions of change ideas. Some may be more relevant to healthcare settings while others are more social care focused. The change ideas are grouped by the secondary driver that they influence. Project teams are encouraged to generate their own change ideas that will help drive change in their local systems. One way of generating ideas is to use the question "How might we?" For example, "How might we engage carers more meaningfully?".

We have made this an interactive document, if you click on the primary/secondary driver it will take you to additional information including tools and resources relating to that driver. At the top of each page of the secondary drivers, there is an arrow  and home button  . The arrow button will take you back to the primary driver page and the home button will take you to the main driver diagram page.

Primary Driver: Early recognition and assessment

Secondary driver	Change ideas			
Use of a structured, holistic assessment approach	Develop process flowchart of steps required for each new admission, for example assessment and care planning approaches	Document early signs of 'stress,' where person centred interventions could be supported prior to distress	Use Stress and Distress Symptom Scale (SDSS)	Daily awareness of any change in cognition e.g. 4AT or SQID
A consistent approach of a multidisciplinary team involved in a person's care to support care planning and delivery that includes people living with dementia and their carers	Use multidisciplinary service rounds and huddles for communication of key information Coloured stickers to indicate where person-centred care plans or personal plans used to inform care planning	Develop a Standard Operating Procedure (SOP) for staff of the roles and responsibilities in person-centred assessment and care planning	Include person-centred care plans or personal plans in admission packs	Use person-centred approaches like active listening, Talking Mats to support good conversations with people

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Evidence and Guidelines:
Mental Welfare Commission: Person centred care plans. Good practice guide
Healthcare Improvement Scotland: Ageing and frailty: standards for the care of the older people

Tools and Resources:
What matters to you?: What matters to you? Resources
Healthcare Improvement Scotland: Improving planned care pathways toolkit
Healthcare Improvement Scotland: Care Co-ordination
Stress and Distress Symptom Scale: To be published, adapted with permission from Moniz-Cook 2001: Challenging Behaviour Scale
Rapid clinical test for delirium: 4AT
NHS Education for Scotland: Introduction to delirium
McCleary E, Cumming P: Improving early recognition of delirium using SQiD (Single Question to identify Delirium): a hospital based quality improvement project. *BMJ Open Quality* 2015;**4:**u206598.w2653. doi: 10.1136/bmjquality.u206598.w2653

Primary Driver: Early recognition and assessment

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Evidence and Guidelines:
Mental Welfare Commission: Person centred care plans. Good practice guide
NHS Education for Scotland: Guide template for developing Standard Operating Procedures
Scottish Government: Shared decision making in realistic medicine. What works

Tools and Resources:
Alzheimer Scotland: Getting to Know Me (GTKM)
Royal College of Physicians: Modern Ward Rounds
Social Care Institute For Excellence: Delivering integrated care: the role of the multidisciplinary team
Healthcare Improvement Scotland: Multidisciplinary team meeting (MDT) Guidance
Talking mats: Talking mats: improving communications, improving lives
Care Inspectorate: Guide for providers on personal planning

Primary Driver: Delivery of proactive person-centred approaches

Secondary driver	Change ideas			
Implementation of person-centred care plans or personal plans for all people living with dementia	Staff document in 'daily logs' the practical implementation of person-centred care throughout the day	Personalised activity planner to support person-centred, meaningful activity	Measurement of the personal outcome for the individual before/ during and after participation in the 'personalised activity	Capture voices/stories/ feedback from people living with dementia and carers on what works well and what could be better
	Meaningful engagement is written in alternative colour in daily logs to evidence participation	Weekly evaluation of participation in meaningful activity for individuals		Develop a communications approach that supports sensitive conversations with people and carers in terms of their culture, language, beliefs and identity
An environment which enables a wide range of meaningful activity in line with the person-centred care plan or personal plan	Make mealtimes a social experience with staff or carers, include personalised food preferences or silicone utensils to reduce noise	Adopt dementia-friendly design principles, for example change layout of dining room, use colour contrast	Use tools to plan activities, for example Cognitive Disabilities Model, Interest and Activities Toolkit, Pocket Ideas Booklet, Reminiscence Therapy, Validation Therapy, Cognitive Stimulation Therapy	Tools available to create a Playlist for Life to manage moments of anticipated stress
	Use tools to develop service environment for example Kings Fund audit, Meaningful Connection Self-Evaluation or EADDT	Work with volunteers to provide outdoor activities, music with massage, touch therapy, exercise etc		Develop personalised resources to reduce stress, for example rummage boxes, sensory items, or 'helping out' to create a sense of purpose

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Evidence and Guidelines:

Mental Welfare Commission: Care plans: how people with lived experience and their friends and family want to be involved

Scottish Government: Shared decision making in realistic medicine. What works

Gwernan-Jones R, Lourida I, Abbott RA, Rogers M, Green C, Ball S, et al: Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews. *Health Services and Delivery Research*, 2020;8(43)

Tools and Resources:

What matters to you?: What matters to you? Resources

Healthcare Improvement Scotland: Person-centred Care Planning Dementia in Hospitals Change package

Healthcare Improvement Scotland: Person-centred Design and Improvement Programme

Primary Driver: Delivery of proactive person-centred approaches

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Evidence and Guidelines:

Brasure M, Jutkowitz E, Fuchs E, Nelson VA, Kane RA, Shippee T, Fink HA, Sylvanus T, Ouellette J, Butler M, Kane RL: Nonpharmacologic Interventions for Agitation and Aggression in Dementia. *Rockville (MD): Agency for Healthcare Research and Quality (US),* 2016 Mar. Report No.: 16-EHC019-EF. PMID: 27099894

Sanatinia R, Crawford MJ, Quirk A, Hood C, Gordon F, Crome P, et al: Identifying features associated with higher-quality hospital care and shorter length of admission for people with dementia: a mixed-methods study. *Health Services and Delivery Research*, 2020;8(22)

Tools and Resources:

Social Care Institute for Excellence: Dementia-friendly environments
Kings Fund and University of Worchester: Enhancing healing environment Tool
Dementia services development centre: Environments for Ageing and Dementia Design Assessment Tool (EADDAT)
Care Inspectorate: Meaningful Connection Self -evaluation Tool
Playlist for life: Make a playlist
Allen Cognitive Group: Cognitive disabilities model
NHS Ayrshire and Arran: Pocket ideas booklet
NHS Dumfries & Galloway: Ideas and Activities Toolkit

Primary Driver: Carers are involved and supported

Secondary driver	Change ideas			
Carers are identified early and involved in the assessment and care planning processes	Include carer identification checklist in admission packs	Establish a process to reliably identify carers and obtain consent to record and share information with staff	Record information from carer on causes of stress and successful approaches to prevent or reduce stress in home environment	Use person-centred approaches to visiting
	Choice of timing and approach for carers to be involved during admission, shared decision making, care planning and improvement processes	Establish process to involve carers as equal partners in all discharge planning conversations	Daily logs are available for carers to see	Work with people and carers to develop life story book to support meaningful activity
Carers needs are identified and supported	Good conversation with carers to identify their experience of stress and distress	Establish a process that provides carers with a single point of contact for example hospital-based carer support workers	Feedback to carers on activities person has engaged with that they could use, for example e-photo frame, music	Develop links with community organisations who support carers for example Meetings Centres, Alzheimer's Scotland Dementia Resource Centres, Carers Centres
	Organise social event that involve carers, for example garden party or concert that can include structured conversations and focus groups	Create a peer group for carers to support wellbeing	Signpost carers to local carer support and training for example Carers Academy, Squarepeg Training	

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Evidence and Guidelines:

Mental Welfare Commission: Carers and confidentiality – good practice guide

Mental Welfare Commission: Care plans: how people with lived experience and their friends and family want to be involved

Gwernan-Jones R, Lourida I, Abbott RA, Rogers M, Green C, Ball S, et al: Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews. *Health Services and Delivery Research*, 2020;8(43)

Scottish Government: Cares (Scotland) Act 2016, Section 28

Tools and Resources:

Schaap FD, Dijkstra GJ, Reijneveld SA, Finnema EJ: Use of dementia care mapping in the care for older people with intellectual disabilities: A mixed-method study. J Appl Res Intellect Disabil. 2021 Jan;34(1):149-163.

Dementia UK: Creating a life story for a person with dementia

Healthcare Improvement Scotland: Improving the Involvement of Unpaid Carers in Hospital Discharge Planning Change Package

NHS Education for Scotland: Equal Partners in Care

Dementia Services Development Centre: Hospital admissions and visits

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Evidence and Guidelines:
NHS Education for Scotland: Dementia skilled improving practice learning resource
Healthcare Improvement Scotland: Supporting carers through hospital discharge The role of hospital-based carer support workers. March 2024
Care Inspectorate: Anne's Law

Tools and Resources:
Meeting Centres Scotland: Find your local meeting centre
Alzheimer Scotland: Dementia Resource centres
University of the West of Scotland: Carers Academy
Care Information Scotland: Carer Centres
Squarepeg Training: Learning disability and dementia course
NHS Education for Scotland: Responding to distress in dementia A staff supported guide for carers
John's campaign: Resources

Primary Driver: Staff are confident and skilled

Secondary driver	Change ideas			
A learning and development culture which supports improvement	Involve a wider range of staff in care planning such as Support Workers and Allied Health Professionals	Support and encourage staff's continual learning and development through wider dementia networks like Dementia Ambassador Group	Share learning about improvement work and learning / development opportunities in noticeboard, learning sessions or newsletters	Organise drop-in sessions for staff to learn about non-clinical approaches to care and support
	Consistent approach to staff development via regular check-ins, personal development reviews, appraisals, experience survey, staff survey or Values Based Reflective Practice	Reflective practice time for staff to 'debrief' on what has gone well	Identify a 'go to' person who can support staff and advise in day-to-day care in response to stress and distress	
Staff are trained to the appropriate level of the Promoting Excellence Framework and the Trauma Knowledge and Skills Framework	Encourage staff to access NHS Education for Scotland for Promoting Excellence Framework or SSSC resources	Develop a Standard Operating/Operational Procedure for staff of the roles and responsibilities in person-centred care planning	Staff training records on promoting excellence, (dementia training programmes) but also reflective accounts on learning from education	Deliver training on assessing changes in cognition and delirium for example 4AT, Dementia Care Mapping
	Create protected time for staff sharing and learning	Monthly team communication to share staff training progress	Develop a staff training matrix to plan, identify skill gaps and provide training	Develop a weekly multi-disciplinary group to assess and manage people living with dementia of differing levels of stress and distress

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	Consistent approach to staff development via regular check-ins, personal development reviews, appraisals, experience survey, or Values Based Reflective Practice	Reflective practice time for staff to 'debrief' on what has gone well	Identify a 'go to' person who can support staff and advise in day-to-day care in response to stress and distress	

Evidence and Guidelines:

Centre for Public Impact, Healthcare Improvement Scotland, Iriss: Human Learning Systems: A practical guide for the curious. 2022

Davies S, Herbert P, Wales A, Ritchie K, Wilson S, Dobie L: Knowledge into action – supporting the implementation of evidence into practice in Scotland. Health Information and Libraries Journal. 2017. 34(1)74-85

Tools and Resources:

Healthcare Improvement Scotland: Community led models: innovation in health and social care report

Healthcare Improvement Scotland: Care Experience Improvement Model (CEIM)

NHS Education for Scotland: Values Based Reflective Practice (VBRP)

Personal Outcomes Network: Personal Outcomes Network

King's Fund: Experienced-Based Co-Design Toolkit

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Evidence and Guidelines:

NHS Education for Scotland: Promoting excellence: A framework for all health and social services staff working with people with dementia, their families and carers

NHS Education for Scotland: Trauma Knowledge and Skills Framework

NHS Education for Scotland: Guide template for developing Standard Operating Procedures

Tools and Resources:

Rapid clinical test for delirium: 4AT

NHS Education for Scotland: Introduction to delirium

NHS Education for Scotland: Equal partners in care (EPiC) - Caring for unpaid carers

University of Bradford: Dementia Care Mapping

NES Dementia Standards: Supporting Change Tool

NHS Education for Scotland: Quality Improvement Zone

NHS Education for Scotland: Dementia

Measurement

Measurement is vital for evaluating and enhancing the quality of care, ensuring accountability, and making informed decisions. A measurement plan sets out details for each measure proposed for an improvement project. NHS Education for Scotland's QI Zone provides more information about Measurement Plans.

Qualitative data is data that involves words. Stories and feedback give rich qualitative data. They are a very powerful way of finding out where opportunities for improvement lie, and of understanding and describing the impact of improvements.

Quantitative data is measureable as a number, including the numbers with a qualitative characteristic. It is possible to convert stories and feedback to numbers by either asking people to express an opinion on a statement using a rating scale like satisfaction or organising qualitative feedback into themes and counting the number in each (for example number of positive stories). NHS Education for Scotland

The following measures are examples for teams to use when implementing reducing stress and distress improvement activity. They are not an exhaustive list and teams should develop their own measures based on the change ideas they are testing locally. Some measures will need adjusted for different settings and to align with different data collection systems.

Measurement

Outcome measures

Outcome measures are used to understand if changes are resulting in improvements towards the aim.

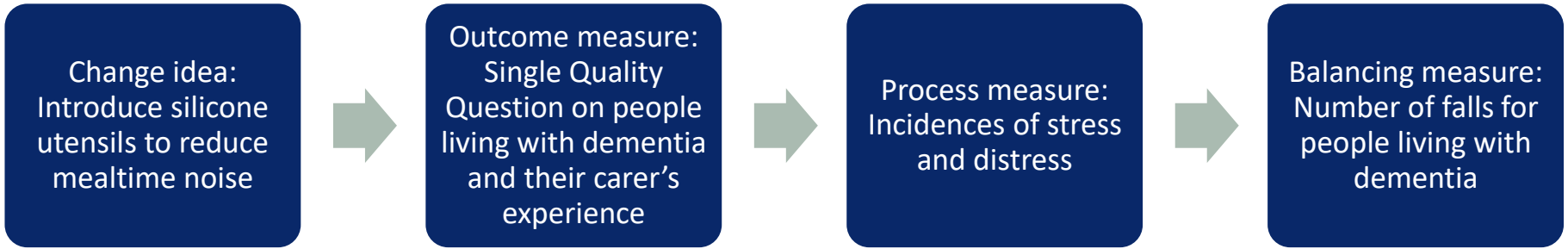
Process measures

Process measures are context specific and depend on the change ideas being tested and implemented.

Balancing measures

Balancing measures are used to check for possible consequences elsewhere in the system (unintended consequences). Balancing measures will depend on the focus of your improvements and some examples below may work better as process measures.

Example of using measures with a change idea



Measurement: Outcome measure

Concept	What/ How to measure
Experience of people living with dementia and their carers	Qualitative data from local systems and processes which seek feedback on the care experience of people living with dementia and their carers. You may wish to use Healthcare Improvement Scotland, Single Quality Questions. "Overall, how helpful or unhelpful has the support [*from/for…*] been to you -helpful, neither helpful nor unhelpful or helpful? Please tell us a bit more about the option you chose: if the support [*from/for…*] made a difference to you please tell us a bit more. If the support [*from/for…*] did not make a difference, please tell us a bit more."

Measurement: Process measures

Concept	What/ How to measure
Participation in meaningful activity (PRO1)	Percentage of people that have participated in personalised and meaningful activity. **Numerator**: The number of people living with dementia within the service who have engaged with meaningful* activities documented within their care plan daily (previous three consecutive days) **Denominator**: Number of care or personal plans reviewed using agreed sample number per week Percentage Calculation: (numerator/denominator) x 100 *Activity will be considered 'meaningful' if it has been identified as important to that person through the person-centred care planning process
Percentage of people living with dementia with a person-centred care plan or personal plan (PRO2)	Percentage of people living with dementia who have a person-centred care plan or personal plan in place. Local teams can define their own essential criteria for person centred care planning **Numerator:** Number of people living with dementia within the service who have a person-centred, structured and individualised approach care or personal plan in place per week **Denominator:** Number of care or personal plans reviewed using agreed sample number per week Percentage Calculation: (numerator/denominator) x 100
Number of incidents of stress and distress (PRO3)	The total number of incidents of stress and distress within the last calendar month. In hospital settings, this is usually recorded as incidents of violence and aggression.

Measurement: Process measures

Concept	What/ How to measure
Getting To Know Me (GTKM) influences the development and delivery of person-centred care plans/personal plans (PRO4)	Percentage of people where there is evidence that GTKM or similar document has influenced the development and delivery of their person-centred care or personal plan. **Numerator:** Number of people living with dementia with a person-centred care plan or personal plan that documents individual preferences via GTKM and how these have been met **Denominator:** Number of care or personal plans reviewed using agreed sample number per week Percentage Calculation: (numerator/denominator) x 100
People living with dementia administered a when-required (PRN) anti-psychotic medicine (PRO5)	Percentage of people living with dementia administered a PRN anti-psychotic medicine. Use of local existing tools if available such as care home Medicines Administration Records (MAR) charts. **Numerator**: The number of people living with dementia who are administered PRN anti-psychotic medication per week **Denominator**: Total number of people living with dementia in the hospital ward or care home per week. Percentage Calculation: (numerator/denominator) x 100
Carers are identified (PRO6)	Percentage of people living with dementia where the outcome of a conversation to identify carer/s is recorded **Numerator:** Number of people living with dementia with a carer identified and recorded **Denominator:** Number of people living with dementia admitted in hospital ward or care home Percentage Calculation: (numerator/denominator) x 100

Measurement: Process measures

Concept	What/ How to measure
Carers have had discussions with staff to identify their support needs (PRO7)	Percentage of carers who have had a discussion about their support needs and the outcome of the discussion recorded **Numerator:** Number of carer records with discussion recorded (including where no support is needed) **Denominator:** Number of identified carers Percentage Calculation: (numerator/denominator) x 100
Staff have appropriate level of knowledge and skills (PRO8)	Percentage of staff who have completed training to the relevant level of the Promoting Excellence Framework (PEF) and have evidence of implementing skills into practice. **Numerator:** Number of staff who have completed the relevant level* of PEF training and have evidence of implementing skills into practice **Denominator:** Number of staff in the ward or care home Percentage Calculation: (numerator/denominator) x 100 *Relevant level (Informed, skilled, enhanced or expertise) will be based on the descriptions in the framework and each staff's role and level of contact with people living with dementia.

Measurement: Balancing measures

Concept	What/ How to measure
Spend on staff for one-to-one observations (BAL1)	Percentage spend on staff for one-to-one observations Use of existing tools if appropriate such as: Excellence in Care, Supplementary staffing use – overtime and excess Excellence in Care, Supplementary staffing use – bank and agency
Total number of hours people living with dementia receive one-to-one observations (BAL2)	The total number of hours people (living with dementia) receive one-to-one observations
Number of falls (BAL3)	**Numerator:** The total number of falls within the last calendar month **Denominator:** The total number of occupied bed days for the month in the service Use of existing tools such as Excellence in Care, Fall rates
Length of stay in hospital (BAL4)	Average length of hospital stay for people living with dementia from admission to discharge in hospital Use of existing tools such as Excellence in Care, Occupied bed days
Number of delayed discharges in hospital (BAL5)	Number of people with delayed discharge in hospital ward

Measurement: Balancing measures

Concept	What/ How to measure
Staff sickness or absence rates (BAL6)	Percentage of hours lost to staff sickness or absence **Numerator:** Number of hours of sickness absence in each month **Denominator:** Total number of hours per hospital ward or care home for all staff Percentage Calculation: (numerator/denominator) x 100
Staff experience and well-being	To determine staff experience and well-being in the service Use of existing local staff experience tools such as: SPSP Safety Climate Resource: Staff Questionnaire

Contact Us

Get in touch to provide feedback or share your plans for using the reducing stress and distress change package by:

Twitter: @online_his

Email: his.focusondementia@nhs.scot

Web: healthcareimprovementscotland.scot

FoD: FoD: Improvement Programmes/Home