Healthcare
Improvement
Scotland

Equality and Human Rights Impact Assessment for PDS and Care Co-ordination Improvement Programme

January 2026

Version 0.1

NHS

Name: Focus on Dementia: Post-diagnostic Support (PDS) and Care Co-ordination Improvement Programme EQIA

Directorate: Nursing and Service Improvement

Team: Shifting the balance of care

Assessment lead: Pamela Campbell

Responsible manager: Stephen Lithgow

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Background

For all new or revised work, Healthcare Improvement Scotland has a legal requirement under the Public Sector Equality Duty to actively consider the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Equality Act 2010.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

Additionally:

- We give consideration to the principles of the Fairer Scotland Duty by aiming to reduce inequalities of outcome that are based on socio-economic disadvantage.
- As the Children and Young People (Scotland) Act 2014 names Healthcare Improvement Scotland as a corporate parent, we must consider the needs of young people who have experienced care arrangements, and young people up to the age of 26 who are transitioning out of these arrangements.
- Per the UNCRC (Incorporation) (Scotland) Act 2024 Healthcare Improvement Scotland must ensure that its activities are compatible with UNCRC requirements.
- If the work will impact islands communities please follow the guidance from Scottish Government here: Island communities impact assessments: guidance and toolkit - gov.scot (www.gov.scot). Island communities are included within this impact assessment template.

EQIA overview

Status	New ☒	Existing ☐
Aim(s)	**People accessing post-diagnostic support (PDS) will receive a high quality, person-led service that meets their individual needs.** Engagement with all teams across Scotland will enable us to further understand the service models currently in place and give a fuller understanding of national post-diagnostic support provision. By embedding the use of the PDS Quality Improvement Framework (QIF) for service self-evaluation and planning for improvement at each participating site, the programme aims to reduce unwarranted variation in the quality of PDS provision.	
Intended Outcome(s)	Building on previous PDS improvement and care co-ordination improvement programmes led by the Healthcare Improvement Scotland (HIS) Focus on Dementia (FoD) team, the next improvement programme will use a quality management system (QMS) approach to support the spread and scale-up of high impact changes including: • **Improving quality** through use of the PDS (QIF) • **Improving care co-ordination** to support people living with dementia who have more complex needs • **Improving personal planning** for future care and support including early conversations about Power of Attorney Evidence and data from our previous dementia programmes show that effective PDS and care co-ordination can lead to improvements in quality of life, reductions in medications, timely discharge from hospital and reduced risk of readmission to hospital. FoD have accepted applications from 16 health and social care partnerships (HSCPs) in Scotland for 2025/2026 and will seek participation with a further 15 HSCPs for 2026/2027. Teams will be supported to implement changes that will result in improvements in outcomes for people and their carers using PDS services across the high impact change described above. This programme forms part of HIS work on the safe delivery of care for older people. It will be delivered in tandem with improvement support offered to HSCPs in relation to improving health and social care services for people living with frailty.	

Is there specific relevance for children and young people?	Yes ☐	No ☒
Are island communities included in the work?	Yes ☒	No ☐

Advancing equality

Age	Risk of dementia increases with age: - Prevalence 0.1% under age 64 years compared to 15.9% of people over 80 years (Source: SIGN) Approx 3,200 people in Scotland have younger-onset dementia and will have different needs (Source: Scottish Government) People with younger-onset dementia can experience difficulties finding and accessing appropriate services (source: Giebel et al 2021)
Positive impact	Older people are well represented in our programme making up the majority people with dementia. People with dementia also includes young onset dementia (under 65). We worked with our PDS Leads Network to develop a specific section for young onset dementia in the PDS Quality Improvement Framework to improve access and support for younger people with dementia across Scotland. A primary driver on our driver diagram for this programme is to ensure equitable access to support for all people with a diagnosis of dementia. We will run project surgeries for our participating teams, the first will focus on young onset dementia pathways. Some teams have highlighted this as a gap following self-assessment and are working to improve the pathways into PDS for this group.
Negative impact	People with young onset dementia can have more challenges in obtaining a diagnosis of dementia and accessing PDS
Neutral impact	

Care Experience	Area not included in either SIGN or Scottish Government EQIA
Positive impact	
Negative impact	
Neutral impact	No evidence has been identified which suggests differential impact for people with experience of care.

Disability	**Frailty** There is a correlation between frailty and dementia (Dementia UK). Scottish data on numbers of people with learning disabilities, and information on dementia and multiple sensory loss (Source: Scottish Government). **Learning disability** • Higher prevalence of dementia compared to general population. • Higher prevalence of younger-onset dementia compared to general population. • People with learning disabilities can experience difficulties in accessing services to meet their needs (Source: Scottish Government). **Loss of hearing or sight** • Both dementia and hearing and slight loss more prevalent in older age groups, therefore likely to be people with dementia with sight and/or hearing loss. • People with dementia and hearing/sight loss more likely to experience difficulties in accessing diagnosis (Source: Scottish Government). • People with hearing loss can have difficulties access diagnosis as many tests involve hearing (Source: NIHR).
Positive impact	People living with dementia in our programme are more likely to be disabled due to their general age and frailty. This includes a range of co-morbidities, including sensory impairment and decreased mobility. As part of their access to health and social care, individuals with dementia will be assessed and supported holistically so that all their needs are met. This is a main principle of the 8 Pillar model of care co-ordination that we are seeking to promote with this programme. Improved care co-ordination locally has been identified as an area for improvement by some teams following self-assessment of their PDS service. Where we hold events, we ensure they and communications are accessible for people living with dementia and their carers, for example meeting online

	where preferred, using accessible venues for events, including quiet zones and good signage for people with dementia, and ensuring films are subtitled. People with a learning disability are at greater risk of developing dementia. Informal carers will be involved throughout this work from scope to evaluation. Support for carers is a critical success factor for the work and is on our driver diagram. We will meet regularly with National Dementia Carers Action Network (NDCAN) and other groups where possible to ensure local engagement with carers.
Negative impact	People with learning disability and LD Teams are not presently included in the improvement programme. They have a right to PDS.
Neutral impact	

Gender Reassignment	Scottish Government and SIGN EQIAs highlight that there is little information on transgender people with dementia (Source: Scottish Government, SIGN). Transgender people have reported discrimination when accessing services, and this may be a barrier for both accessing services and disclosing their identity when accessing services (Source: Scottish Government). Problems with memory may impact on taking medication including hormone therapy Problems with memory may mean that gender and body identities may not match (Source: LGBT Health & Wellbeing) An older person may choose to transition (Source: Age Scotland)
Positive impact	As part of their access to health and social care, individuals with dementia will be assessed and supported holistically so that all their needs are met. This is a main principle of the 8 Pillar model of care co-ordination that we are seeking to promote with this programme.
Negative impact	We recognise however that people with dementia who are trans/transgender may experience distress around: • recalling transition, disclosure, outing and confidentiality

	- attitudes and assumptions, and - hormones and overlap with other medication.
Neutral impact	

Marriage and Civil Partnership	Scottish Government and SIGN EQIAs highlight that there is no information (Source: Scottish Government, SIGN). While applicable to anyone living with another person, and not referring directly to marriage or civil partnership, highlights evidence that if a person lives alone, there are fewer opportunities for others to notice their symptoms (Source: Arblaster). Most carers (55%) participating in this research were spouses. The research found that unpaid carers play a key role in seeking appropriate support for the person they care for (Source: Giebel et al 2021).
Positive impact	As part of their access to health and social care, individuals with dementia will be assessed and supported holistically so that all their needs are met. This is a main principle of the 8 Pillar model of care co-ordination that we are seeking to promote with this programme.
Negative impact	
Neutral impact	

Pregnancy and Maternity	Scottish Government highlight data gap (Source: Scottish Government). Although the SIGN guideline highlights that this strand was not a key issue for the guideline, they highlight potential issues for pregnancy and early-onset dementia in their EQIA (Source: SIGN).
Positive impact	
Negative impact	
Neutral impact	There is no evidence identified to suggest any impact.

Race	Scottish Government highlight data gaps related to minority ethnic groups, including: - Available data on the number of people from minority ethnic communities with dementia. - Information on Gypsy/Traveller communities (Source: Scottish Government). - Increased prevalence for particular types of dementia in some ethnic minority communities (Source All-Party Parliamentary Group) - Evidence that number of people with dementia from ethnic minority groups will rise (Source: Alzheimer Europe). - Scottish Government highlight increasing prevalence, but low uptake of services by minority ethnic communities in Scotland (Source: Scottish Government). - Number of reasons including lack of cultural appropriate services, language barriers, cultural beliefs and stigma related to dementia (Source: SIGN, Alzheimer Europe).
Positive impact	We will work with our teams to conduct a self-evaluation to consider improvement which will lead to more equitable access to everyone in their community. We can potentially use PHS PDS data around ethnicity to identify gaps.
Negative impact	We know from the wider literature that people from minority ethnic groups do not have equitable access to PDS and care co-ordination. People should have equity of access to services, however access to care may be impacted by availability of information in specific languages and variations in understanding and cultural views around dementia. If someone has a first language, they may feel more fluent, comfortable or have better cognition of it and revert to it, which may cause communication issues. - Sense of isolation if in white institutional culture. - Culturally appropriate knowledge of staff / links with community.

	- May only have access to long-term memories from when they experienced overt hostility.
Neutral impact	

Religion or Belief	Scottish Government highlight resources provided by religious groups to support dementia care (Source: Scottish Government).
Positive impact	Person centred care planning and support from PDS practitioners should take the person's spirituality into account. We will work with team to improve personal planning as a key element of PDS.
Negative impact	
Neutral impact	

Sex	Higher prevalence among women, not accounted for by longer life expectancy (Source: Alzheimer Europe) • 67% of people with dementia are women (Source: SIGN) Highlight inequities in quality of health care received by women and that sex difference is not always considered in medical research (Source: Alzheimer Europe) Women are more likely to provide formal and informal care (Source: Alzheimer's Disease International) Highlights evidence that gender roles and norms may impact men accessing diagnosis (Source: Alzheimer Europe)
Positive impact	Given the higher prevalence in women, improving PDS and care co-ordination is likely to have more of a positive impact on women.
Negative impact	Women are well represented in the client group as dementia has a higher incidence in women. Gender should not impact on care however we need to be aware of services favouring one sex over the other for example day opportunity activities catering mainly for women.
Neutral impact	

Sexual Orientation	Memory problems may mean they have problems remembering who they have told about their sexual orientation (Source: Alzheimer's Society), may remember older memories, or be concerned about who they have shared information with (Source: Age Scotland) Highlights that LGBT people may have previously homophobia/ transphobia when accessing a service which may be a barrier for accessing services (Source: Alzheimer's Society). Services available do not always meet the needs of LGBT people (Source: Alzheimer Europe) LGBT people may have different support networks, and there is need to ensure they stay connected to their network and to the LGBT community (Source: LGBT Health & Wellbeing). LGBT carers will also have specific needs (Source: LGBT Health & Wellbeing).
Positive impact	We will support teams to improve equitable access to services and their practice around personal planning.
Negative impact	As dementia progresses, LGBT people may feel like they are back in an earlier time in their life where they felt less acceptance and this could cause distress. • Being out, to what extent and to whom/returning to closet/disclosure • Outing and confidentiality • Reminiscence work, which can be therapeutic for many people with dementia, may distress but could also be a positive experience if tailored to the individual • Attitudes and assumptions, perception of institution and safety • Socialising and maintaining links with (LGBTQ+) community/isolation/reference points (queer culture/music/TV) Relations – less likely to have children and more likely to be estranged from family. Family/loved ones may be 'chosen family'. Sensitivity required in supporting Life Story work.
Neutral impact	

Socio-economic	Highlights link between socio-economic status and digital access (Source: Scottish Government). Highlights evidence that high levels of deprivation may be associated with higher diagnosis rate. Highlights evidence that deprivation may impact diagnosis – for example, more likely to have other health conditions which may be prioritised (Source: Arblaster)
Positive impact	We include all areas in our selection process to ensure a fair representation of different demographics across Scotland. PDS data returns to Scottish Government now includes data relating to deprivation levels HSCP level. We will be able to monitor inequalities at this level.
Negative impact	People from lower incomes or in deprived areas are more likely to develop dementia. We will work with selected teams to use available data to better understand their population and how socio-economic issues might affect access to services and support.
Neutral impact	

Island communities	There is evidence on rural communities which may be applicable however the Scottish Government also highlight there is little information on rural communities (Source: Scottish Government). Thinking about rural communities (not island communities specifically): • May be fewer services to access. • May also experience barriers in accessing digital services (Source: Scottish Government). • Evidence of higher prevalence of dementia in rural communities. • Evidence that people in rural communities often access diagnosis later. • Evidence that there are fewer opportunities to identify symptoms. (Source: Arblaster).
Positive impact	All areas of Scotland are invited to participate in the collaborative and have access to our Learning System resources.

	The PDS Leads from our island communities attend our PDS Leads Network meetings, which we have changed to virtual to improve access/attendance. We are working with island/rural teams to ensure all demographics are reflected in the programme. Shetland and Orkney are in cohort 1 of the programme, also Borders, Dumfries & Galloway and Aberdeenshire. We have undertaken visits to the island teams to further understand the challenges in providing PDS services – such as dispersed islands, access during poor weather/winter to isolated communities and the ability to offer appropriate support to smaller groups such as those living with young onset dementia.
Negative impact	PDS service can have difficulty accessing more remote areas of the island communities – especially in the winter months
Neutral impact	

Overcoming negative impacts

Protected characteristic	Actions	Person responsible
All characteristics	Evidence and Evaluation for Improvement Team (EEvIT) supported us to carry out an evidence review on inequitable access to PDS across all protected characteristics.	Each site completing a self-evaluation which includes accessibility and equality of opportunity.
Age	Young Onset Dementia – We will raise awareness of this with PDS Leads and it will be an ongoing theme. We will provide a PDS project surgery for our teams in cohorts 1 and 2 and forge connections with experts. We will support teams looking to improve YOD pathways.	FoD – SL/JM
Care experience	Nil	
Disability	Carers will be involved throughout the process nationally. Teams will be asked to ensure carer participation throughout and to ensure change ideas consider carers as well as the person living with dementia. Any face-to-face events will be in accessible venues. We will ask stakeholders how we can support participation. We will work with partners to scope PDS and staff learning needs for people with learning disabilities (LD) and dementia. We will also promote the publication of our learning disabilities and advanced dementia guidance document – My New Home.	FoD – SL/JM

Protected characteristic	Actions	Person responsible
	We have and will continue to feature LD at our PDS Leads network. We will explore working with a LD team from Clacks and Stirling in year 2 of the programme	
Gender reassignment	Each site completing a self-evaluation to identify change areas. We will support teams to consider how transgender people who have dementia are supported. We will work with our teams to conduct their own self-assessment and to consider improvement which will lead to more equitable access to everyone in their community.	FoD – SL/JM
Marriage/civil partnership	Nil	
Pregnancy and maternity	Nil	
Race	We will work with our teams to conduct their own self-assessment and to consider improvement which will lead to more equitable access to everyone in their community.	FoD – SL/JM
Religion or belief	Nil	
Sex	Where appropriate we will support participating site staff to consider the needs of men and how they might differ as part of the holistic approach to support.	FoD – SL/JM
Sexual orientation	We will work with our teams to conduct their own self-assessment to consider how people from LGBTQ+ communities are supported. We will share the LCT resource to support practice (see Evidence and Research list below).	FoD – SL/JM

Protected characteristic	Actions	Person responsible
Socio-economic	We will work with our teams to conduct their own self-assessment to consider how people from areas of deprivation in their catchment area are supported.	FoD – SL/JM
Island communities	We will conduct site visits when possible and we will explore some budget allowance to support travel to events. Virtual access to meetings and resources. Use of virtual support and other available health/social care/third sector practitioners in remote areas to support PDS Island reps at PDS Leads meetings. Island communities as part of our collaborative (Orkney and Shetland in cohort 1).	FoD – SL/JM

Impact rating

Impact Rating Key

Low 🟢	There is little or no evidence that some people are (or could be) differently affected by the work.
Medium 🟡	There is some evidence that people are (or could be) differently affected by the work.
High 🔴	There is substantial evidence that people are (or could be) differently affected by the work

Protected characteristic	Low	Medium	High
Age	🟢		
Care experience	🟢		
Disability	🟢		
Gender reassignment		🟡	
Marriage/civil partnership	🟢		
Pregnancy and maternity	🟢		
Race		🟡	
Religion or belief	🟢		
Sex	🟢		
Sexual orientation		🟡	
Socio-economic		🟡	
Island communities	🟢		

Stakeholder collaboration

Protected characteristic	Organisation / Team / Person	Contact details
Wendy Rankin	NDCAN/SDWG	c/o Alzheimer Scotland
Maureen Taggart	PDS Executive Lead	Alzheimer Scotland
Rosie Tyler-Greig	Community Engagement, HIS	HIS

Monitor and review

Identified issue	Person responsible	Review date
We have reported above on issues already known to impact negatively on specific groups and the actions we will take. Our programme aims to support participating teams to consider and mitigate these issues in their improvement work. We will monitor this throughout the programme.	Stephen Lithgow Julie Miller	January 2027

Evidence and research

Evidence and research	Attached information
EQIA (SIGN)	
“A piece of paper is not the same as having someone to talk to”: accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities Giebel et al 2021	
Ethnic minority communities Increasing access to a dementia diagnosis (Alzheimer's Society) September 2021	
Dementia Projects for Minority Ethnic Communities Blake Stevenson 2020	
Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities (All-Party Parliamentary Group on Dementia) July 2013	
Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research Alzheimer Europe 2019	
Charter of Rights for People with Dementia and their Carers in Scotland 2009 Cross Party Group on Alzheimer’s	
Equalities Knowledge Map – evidence review of inequitable access to PDS Conducted by EEvIT for Focus on Dementia (2022)	
Proud to Care: LGBT and Dementia: A Guide for Health and Social Care Providers	
Dementia action plan: equality impact assessment - Coronavirus (COVID-19): Scottish Government March 2021	
The Impact of Dementia on Women: Alzheimer's Research UK May 2022	

Women and Dementia: A global research review: Alzheimer's Disease International June 2015	
LGBTQ+: Living with dementia: Alzheimer's Society	
Rights of LGBTQ+ Older People in Scotland: Age Scotland May 2024	
The development of intercultural care and support for people with dementia from minority ethnic groups: Alzheimer Europe	

Appendix A

UNCRC Checklist

Not relevant

EQIA sign off

Please ensure the project lead is satisfied with the assessment and that you retain a copy for your records

If you need any advice on completing this form, or any aspect of the Equality Impact Assessment process, please contact the Equality, Inclusion and Human Rights Manager rosie.tyler-greig@nhs.scot

Project lead	Stephen Lithgow
Sign-off date	8 January 2026