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A Quality Improvement Framework for Dementia Post-Diagnostic Support in Scotland

Second Edition

December 2021

Published December 2021

www.healthcareimprovementscotland

Contents

Introduction

The purpose of this document is to set out what is expected from high quality dementia post-diagnostic support (PDS) services in Scotland. It is influenced by the outcomes that people should experience as a result of good post-diagnostic support and the criteria that support these outcomes to be achieved. The document is for:

- practitioners delivering post-diagnostic support, and
- managers of post-diagnostic support services.

Focus on Dementia led on this second edition of the framework. The original was published in September 2018 and its development was also led by Focus on Dementia with the help of the Post-diagnostic Support Quality Group (a group set up by Focus on Dementia). The framework was further developed with the support of a range of health and social care practitioners, third sector, policy, improvement and education colleagues, people with dementia and those who care for them. This second edition has also been produced collaboratively. It reflects changes to practice necessitated and influenced by working in a COVID-19 context and by feedback from those who used the first edition.

Focus on Dementia is the national improvement programme for dementia in Scotland, based within Healthcare Improvement Scotland's Improvement Hub (ihub). We work in partnership with national organisations, health and social care partnerships, people with dementia and those who care for them to improve the quality of care and support. Taking a whole pathway approach, our work supports improvements in:

- diagnosis and post-diagnostic support
- integrated care co-ordination in the community
- care of people with dementia in hospitals, including specialist dementia units, and
- advanced care.

In partnership with Alzheimer Scotland and NHS Education for Scotland (NES), a post-diagnostic support network was established in 2017 to support learning and improvement for all practitioners delivering dementia post-diagnostic support in Scotland. This network continues to thrive and is now a wider dementia practitioner network. Focus on Dementia also facilitate the National Post-Diagnostic Support Leads network which meets quarterly.

Background to improving post-diagnostic support for people with dementia in Scotland

In 2011, Alzheimer Scotland launched the 5 Pillars model of post-diagnostic support[1]. The purpose of post-diagnostic support is to equip people living with dementia, and those who care for them, with the tools, connections, resources and plans they need to live as well as possible and prepare for the future. Informed by Alzheimer Scotland's 5 Pillars model of post-diagnostic support, Scotland's second National Dementia Strategy[2], published in April 2013 set out the target that all people newly diagnosed with dementia will have a minimum of one year's post-diagnostic support co-ordinated by a named Link Worker, including developing a person-centred support plan.

Scotland's National Dementia Strategies[2, 3] continue to emphasise the importance of prioritising the development of post-diagnostic support in Scotland and the Local Delivery Plan Standard[4] continues to state that people newly diagnosed with dementia will have a minimum of one year's post-diagnostic support co-ordinated by a named Link Worker. The Dementia and COVID-19 – National Action Plan[5] to continue to support recovery for people with dementia and their carers also continues to emphasise this commitment.

Why do we need this framework?

Whilst statistical data on post-diagnostic support is collected, there has been no national mechanism for assuring the quality of the support people are receiving. We know from speaking to people with dementia, those who care for them, practitioners and other professionals that approaches to post-diagnostic support and the quality of post-diagnostic support services vary throughout the country.

This framework therefore aims to set out what is necessary for high quality post-diagnostic support and the policies, principles, rights and standards that should underpin service provision (see Appendix 3). By using the principles of personalisation and personal outcomes, the framework is relevant for post-diagnostic support practitioners working with people across the 5 Pillars model[1] and takes into account situations where people are not diagnosed until they are in the middle stages of their dementia but are still eligible for, and offered, post-diagnostic support whilst requiring more care co-ordination as described by Alzheimer Scotland's 8 Pillars model[6]. There are references throughout the framework and guidance to acknowledge this.

The words 'post-diagnostic support practitioners' are used throughout the framework to cover Dementia Link Workers and all other staff who deliver post-diagnostic support as the named practitioner.

Why use the framework?

The key benefits of using the framework are:

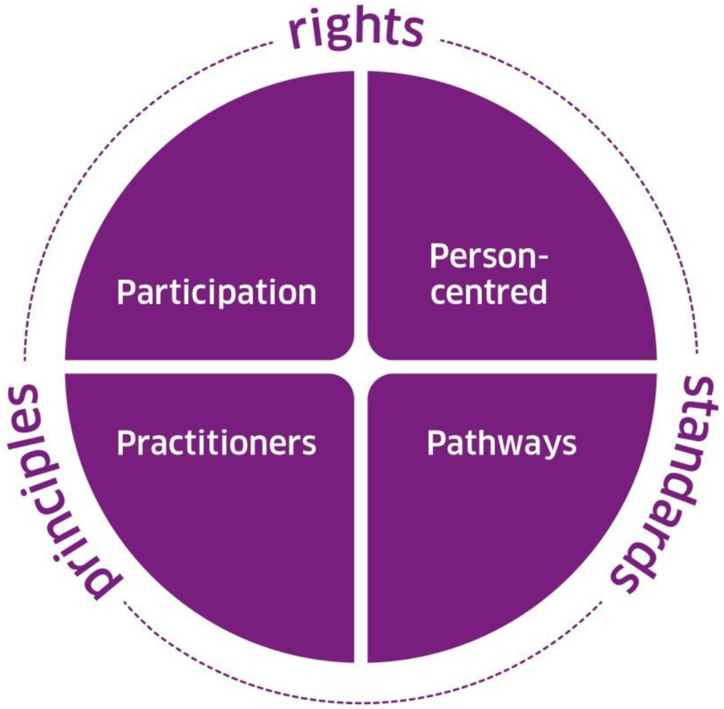
- to explore how well the post-diagnostic support service is supporting positive outcomes for people with dementia and those who care for them
- to improve the experience of practitioners delivering post-diagnostic support
- to improve local decision-making to ensure staff have the necessary skills and resources to deliver high quality post-diagnostic support
- to act as a motivator for service improvement
- to provide a quality assurance system for post-diagnostic support
- to provide quality assurance evidence for any external scrutiny bodies such as the Care Inspectorate
- to inform national policy, education and improvement programme priorities, and
- to ensure that services are delivered to a consistently high standard.

Have a look at the short animation and case studies[a] to learn how others have used it.

Key enablers to high quality post-diagnostic support

The framework is influenced by four key areas which are essential for the delivery of high quality post-diagnostic support (see Figure 1).

Figure 1: The key areas of post-diagnostic support



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[a] ihub.scot/improvement-programmes/focus-on-dementia/improving-diagnosis-and-post-diagnostic-support/using-the-quality-improvement-framework/

A clear business case will sustain the delivery of post-diagnostic support and create conditions for the service to flourish. The necessary resources, leadership support, mainstream funding and clear commissioning intentions based on robust local data will support high quality provision. Measurement to demonstrate the benefits of post-diagnostic support and, in turn, the economic benefit to organisations, supported by case studies reflecting the real-life experience of post-diagnostic support, will assist the business case. The driver diagram in Figure 2 below illustrates the overall aim of the framework and the main factors that contribute to achieving the aim:

- the primary drivers are the personal outcomes people can experience as a result of receiving high quality post-diagnostic support
- the secondary drivers are the four key areas in Figure 1 that underpin the outcomes, and
- the change ideas are the quality criteria – the practical things that need to be in place to meet the aim.

Figure 2: Driver diagram for high quality post-diagnostic support

Aim	Primary drivers	Secondary drivers	Change ideas
High quality post-diagnostic support is delivered to everyone newly diagnosed with dementia	I experience high quality post-diagnostic support at the right time and at the right level for me	Pathways	Quality criteria
	I am confident in the people who support me following my diagnosis	Practitioners	
	I know more about my dementia and have adjusted to my diagnosis	Participation	
	I feel listened to and what matters to me is at the heart of decisions about me	Person-centred	
	I feel better about the future knowing I have made plans		

Next steps

The framework is available for all post-diagnostic services and practitioners to use.

You are welcome to feedback on any aspect of the process to the Focus on Dementia team: his.focusondementia@nhs.scot.

We will gather all feedback to support further improvements to the framework which will be reviewed in April 2024, or earlier if necessary, to take any developments into account with respect to Scotland's fourth dementia strategy when it is published.

A 'companion' resource called 'Making the most of your post-diagnostic support[b]' was also developed with and for people with dementia and carers and was published in January 2020. It was produced in collaboration with Alzheimer Scotland, the Scottish Dementia Working Group and the National Dementia Carers Action Network. It can be accessed on the ihub website[c] and hard copies can be ordered from info@alzscot.org. This resource explains to people newly diagnosed with dementia that they are entitled to post-diagnostic support, explains what a good service looks like and helps them to plan their support.

Any other comments or queries to the Focus on Dementia team, Healthcare Improvement Scotland.

his.focusondementia@nhs.scot
ihub.scot/focus-on-dementia/
@FocusOnDementia

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[b] ihub.scot/media/6939/making-the-most-of-your-entitlement.pdf

How to use the framework

The framework has been set up as a self-assessment tool to help post-diagnostic support practitioners and service managers consider:

- where their service meets the criteria
- where certain aspects could be improved, and
- where a clearer business case is necessary to ensure the service has the appropriate resources to operate as described by the framework.

It is not a questionnaire to be used with people with dementia and those who care for them. The service will have separate methods for gathering such feedback.

The framework is influenced by personal outcomes the person with dementia can experience as a result of receiving high quality post-diagnostic support. As such, each section of the framework is headed by a personal outcome written in the first person and a set of quality criteria for service provision has been assigned to each outcome. There are Yes and No columns against each criterion and a section for briefly recording the source of evidence and/or any comments. Post-diagnostic support practitioners should reflect on each of the criteria and if they believe their service meets the criterion then the Yes column can be marked. If there is room for improvement then the No column is marked.

The guidance note in Appendix 1 suggests how each criterion could be evidenced. It is anticipated that a post-diagnostic support service improvement plan can be drawn up for the areas that a service wishes to improve on and this can be further organised into the top three priorities for improvement (see Appendix 2 for an example improvement plan template).

The use of the framework is optional, and the frequency and method of using the framework can be locally determined. It is recommended it be used:

- as a guide when setting up a new service
- at least annually as a self-assessment and more frequently if required
- to audit or peer audit existing services to inform service improvement
- as a team exercise, and
- by individual practitioners who wish to self-assess their practice against relevant criteria which, in turn, can inform discussions at personal development reviews.

The Post-Diagnostic Support Quality Improvement Framework

See Appendix 1 for guidance on sources of evidence for each of the quality criteria.

1. I experience high quality post-diagnostic support at the right time and at the right level for me			
Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
a. Post-diagnostic support is offered, planned and delivered at a pace and in an order that reflects the person's needs and assets.			
b. Individuals are asked how they'd prefer to connect with the service, for example to meet in person and be visited at home, to use a digital platform or to have a blend of both.			
c. The service has approved arrangements in place for using technology to connect with individuals and follows best practice principles when using virtual methods, for example the Social Care Institute for Excellence guidance[7].			
d. There is equitable access to post-diagnostic support irrespective of factors such as the person's age, race, sexuality, residence, background and ability to use technology to engage with the service.			
e. Information about the service is provided in a language and format that is easy to understand.			
f. Individuals who are diagnosed in the middle stages of their dementia, and whose needs would be more effectively met by another available practitioner or service, are referred on appropriately.			

1. I experience high quality post-diagnostic support at the right time and at the right level for me

Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
g. The service is able to recognise the need for urgent post-diagnostic support and, if possible, can prioritise or fast track referrals.			
h. The service works closely with others to ensure the person's care and support is well co-ordinated and delivered by the right people for the stage of their dementia and the needs that they have.			
i. The service has approved arrangements in place for sharing personal information appropriately.			
j. The person and those who care for them are clearly informed of different agencies that can support them, and have provided appropriate consent to be referred to these.			
k. The post-diagnostic support practitioner has a clear understanding of the roles of other professionals, referral routes, reason for referral, including any rehabilitation needs, and can support access to these.			
l. Clear communication and careful planning and support is provided to empower the person to self-manage their condition, where possible, prepare for the future and, where applicable, for being discharged from post-diagnostic support.			
m. The post-diagnostic support practitioner records the person's status when post-diagnostic support ends, for example if the person is self-managing or has been referred to another service.			

1. I experience high quality post-diagnostic support at the right time and at the right level for me

Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
n. The person and those who care for them are given contact information so that they know how to access the service should they initially decline support or leave the service early.			

2. I am confident in the people who support me following my diagnosis			
Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
The practitioner delivering post-diagnostic support: a. Has a clear remit and dedicated time and resources to carry out their role.			
b. Has good communication skills and the ability to build trust and develop strong relationships based on what matters to the person and those who care for them.			
c. Has the key knowledge and skills to support the person and those who care for them as outlined in the Promoting Excellence resources[8, 9] (see link in Appendix 3). This includes the ability to engage with the person via technology if the person chooses this as a preferred method.			
d. Is reliable, proactive and creative, providing consistent support at a pace that reflects the person's post-diagnostic support needs and of those who care for them.			
e. Actively seeks feedback from the person and those who care for them on the experience of post-diagnostic support, what's gone well and what could be improved. This includes being part of a national initiative to capture an overall measure of the difference post-diagnostic support makes[10].			
f. Supports the person's ability to keep in touch with contacts who can provide support.			

2. I am confident in the people who support me following my diagnosis

Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
g. Informs the person and those who care for them about available activities, opportunities and online resources and, where required, supports access to these.			
h. Can suggest strategies, simple equipment, straightforward therapeutic interventions and everyday adaptations to the person’s home and personal life, and can refer on to other professionals if more complex environmental adaptations are required, to help the person remain independent for as long as possible.			
i. Can access advice on driving and assisted travel options.			
j. Can provide information about accessing and using technology to connect with others and on assistive technology to promote independence, and consider any advance consent requirements, to help the person remain independent for as long as possible.			
k. Receives regular support and supervision which allows for reflection on personal outcomes-focused approaches and supervision of caseload.			
l. Has access to peer support networks, post-diagnostic support resources and appropriate administrative support to keep administrative tasks to a minimum.			
m. Informs relevant health and social care and housing services in their catchment area: of the post-diagnostic support service; how to inform people about it; how to make referrals; if someone they are supporting is receiving post-diagnostic support.			

2. I am confident in the people who support me following my diagnosis			
Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
n. Has an understanding of the national commitment on post-diagnostic support and how their role contributes to meeting the commitment.			

3. I know more about my dementia and have adjusted to my diagnosis

Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
a. The post-diagnostic support practitioner has, or can access, the necessary knowledge to be able to provide the person and those who care for them with information on the type of dementia that affects them.			
b. Support is provided to enable the person to develop strategies to manage, and adapt to, living with their particular type of dementia and to manage risks, for example, attending to physical health needs and going out safely using tools including Herbert Protocol[11] and Purple Alert[12].			
c. Those who care for the person are supported to develop strategies to manage, and adapt to, caring for the person with dementia and to maximise and complement existing strengths.			
d. The person has access to peer support.			
e. Those who care for the person have access to a range of support resources that meet their needs.			

4. I feel listened to and what matters to me is at the heart of decisions about me

Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
a. The person agrees to being referred for post-diagnostic support, is fully involved in identifying and agreeing what kind of support they need and in any follow-up and monitoring.			
b. Where the person chooses not to engage with the service, this right is respected if concerted efforts to encourage take up of support prove unsuccessful.			
c. What is important to the person and those who care for them, and any other information used to support decision-making, is clearly recorded and shared appropriately.			
d. The person is empowered and enabled to make the most of their strengths and achieve what matters to them.			
e. The person is supported to continue to be included in their community.			
f. The person is supported to maintain doing activities that are important to them.			
g. The person is enabled to communicate in a way that is right for them. The post-diagnostic support practitioner can access advice on the different approaches that may support the person with this.			
h. Those who care for the person are listened to and supported in their caring role.			

5. I feel better about the future knowing I have made plans

Quality criteria for the service (how to support the above outcome)	**Yes**	**No**	**Evidence/Comments**
a. The post-diagnostic support practitioner is equipped to empower and support the person and those who care for them to discuss and make plans for the future.			
b. The person is supported at the earliest opportunity to develop a personal plan which reflects what matters most to them and clearly details their wishes.			
c. The person and those who care for them are supported to make practical arrangements, for example claiming benefits they are entitled to, accessing self-directed support and setting up Powers of Attorney.			
d. The person is supported to find out how to participate in research if this is something they wish to do.			
e. With the person's permission, the post-diagnostic support practitioner shares relevant information with the person's GP to inform their Key Information Summary (KIS)[13].			

Appendix 1: Guidance on suggested sources of evidence for the quality criteria

1. I experience high quality post-diagnostic support at the right time and at the right level for me	
Quality criteria	**Suggested evidence**
a.	The support begins with an outcomes-focused conversation on what is most important to the person and how much input they would like and when they require the support. Key aspects of this conversation should be captured somewhere in the person's file, for example in a support planning document or continuation notes. See Appendix 3 for resources to learn more about personal outcomes and outcomes-focused conversations. Feedback from individuals on their experience of post-diagnostic support.
b.	Support planning assessments identify and record information on how the person prefers to connect with the service and what support they might need with respect to their chosen method.
c.	The service can demonstrate that it has considered and approved arrangements for using technology to connect with individuals and follows best practice principles[7] when using such methods. This could include having a Standard Operating Procedure in relation to supporting people virtually, having training sessions for staff on principles of best practice and being able to evidence a person-centred approach when using technology.
d.	The service can demonstrate that it does not discriminate against anyone within their catchment area who could benefit from post-diagnostic support. This might be evidenced through: • equality and diversity training for staff • carrying out an Equality Impact Assessment of the service • supporting people to access and use technology such as helping with Near Me practice tests • team reflection on diversity • recording of protected characteristics; accessing specific resources such as the Lesbian, gay, bisexual and transgender (LGBT) and dementia toolkit (www.dementiavoices.org.uk/wp-content/uploads/2021/03/LGBT-Dementia-Toolkit.pdf), and • accessing translation services and producing anonymised case studies.

1. I experience high quality post-diagnostic support at the right time and at the right level for me

Quality criteria	Suggested evidence
	Note: The Public Health Scotland PDS dataset includes recording of equality data.
e.	The service leaflet/information meets best practice guidance for written literature for people with dementia, for example see the DEEP Guide - Writing dementia-friendly information[14]. Evidence of involvement of people with dementia and those who care for them in the development of information, for example records of meeting attendance, feedback on drafts, and focus groups. Feedback from individuals on how accessible the PDS service information is.
f.	The service can demonstrate that the person has been assessed as having needs that are better met by a different service and date of referral to this service is documented.
g.	Once a person has been referred to the PDS service and it is apparent or becomes apparent, that they need urgent input, for example has a rapidly deteriorating dementia or is in a high risk situation that the service could mitigate with quick intervention, then the service can demonstrate that it has the ability to triage and prioritise referrals rather than operate a standard 'first come first served' waiting list.
h.	The service considers how well the person's care and support is co-ordinated and explores options for good care co-ordination. See the Twelve Critical Success Factors for Care Co-ordination and associated self-assessment tool[15].
i.	The service adheres to strict information governance protocols; data protection is included in policy and procedures and covered in staff training.
j.	The service seeks and records appropriate consent from the person with dementia and those who care for them in order to share information with other agencies who can help.
k.	The PDS practitioner knows about other professionals who can support the person and how to refer to such services. This covers a wide-range of professionals, key ones being Allied Health Professionals (AHPs) such as Occupational Therapists, Speech and Language Therapists, Dietitians, Physiotherapists and Podiatrists (see link to Connecting People Connecting Support framework[16], to Connecting you to Support[17] in Appendix 3 and helpful evidence based self-management resources at www.alzscot.org/ahpresources for further information). Other important services include Social Workers, Community Psychiatric Nurses, Welfare Rights Advisors, Dementia Advisors, Carer Centres and Carer Support Workers.
l.	The PDS practitioner is able to articulate the benefits of accepting PDS to the person and those who care for them and tailor their approach to the individual. Evidence of this may include the use of the *'Making the most of your post-*

1. I experience high quality post-diagnostic support at the right time and at the right level for me	
Quality criteria	**Suggested evidence**
	diagnostic support' booklet'. The booklet can be viewed at the ihub website[d] and order free copies from info@alzscot.org. A case study[e] on its use can also be viewed on the ihub website. The PDS practitioner is confident in broaching the subject of advance planning, encouraging people to think about what is important and making a note of this. If the person's dementia is diagnosed at a later stage, the ability to self-manage may have diminished therefore alternative approaches should be used such as making use of carer/family input and exploring the person's known past wishes to assist with future planning. This could be evidenced in support planning and personal planning documents/tools.
m.	If the person leaves the service the reason is recorded in their file and in Public Health Scotland data reporting.
n.	The person and those who care for them are provided with contact details for the service so that they can get back in touch should they need it. The service could record this in the person's file and/or include this information in any discharge letter to the person.

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[d] ihub.scot/media/6939/making-the-most-of-your-entitlement.pdf

[e] ihub.scot/media/8809/using-the-making-the-most-of-your-pds-guide-to-support-delivery-of-pds-in-fife.pdf

2. I am confident in the people who support me following my diagnosis

Quality criteria	Suggested evidence
a.	The PDS practitioner has a job description that describes and incorporates their PDS role. They can clearly describe their role and any issues with remit and time are raised and addressed through support and supervision sessions and actions from these are recorded.
b.	The PDS practitioner knows how to conduct an outcomes-focused conversation with individuals to determine what matters to them. Evidence of this may also include completion of the Getting To Know Me document[18], personal planning documentation and feedback from people with dementia and those who care for them. Relationship-building and listening to all involved is also an integral part of 8 Pillars support[6]. Where the person is not in the early stages of their dementia, evidence could include use of reminiscence and other approaches to help determine important information about the personal thoughts and wishes of the person - making a connection with someone through their past can help with present and future planning.
c.	The PDS practitioner is trained as a minimum to Skilled Level of the Promoting Excellence Framework and has a development plan that addresses any skills and knowledge that need to be attained to meet Enhanced Level. The PDS practitioner is confident in using, or is supported to use and has access to, technology such as Attend Anywhere (Near Me), Zoom and Microsoft Teams. There may also be evidence that the team know about, and have worked through, the NES and Scottish Social Services Council resource Promoting Excellence in Supporting People Through a Diagnosis of Dementia[9]. Feedback from individuals on their experience of PDS.
d.	The PDS practitioner has a clear plan and structure of supporting the person, and the person’s preferred pace, method and level of support is documented. The support is not ad hoc unless the person has clearly requested that they would prefer ad hoc contact; this preference is recorded. Reliability, proactivity and creativity can be evidenced through personal planning and feedback from individuals.
e.	The service routinely seeks feedback from individuals on how the PDS service is making a difference and what could be better. This may be through the use of a questionnaire, focus groups, other feedback methods such as Emotional Touchpoints or Talking Mats and writing up case studies. The request for feedback should include asking the person and those who care for them if they have felt listened to. The service should embed the Single Quality Question for PDS into its evaluation methods to support the national picture of the quality of PDS[10].

2. I am confident in the people who support me following my diagnosis

Quality criteria	**Suggested evidence**
f.	Personal planning identifies natural networks and any strategies in place to establish and maintain contacts, including the use of the connecting virtually online. For those with more progressed dementia, records may show reliance on others to maintain contacts with them to ensure support is offered.
g.	The PDS practitioner knows or finds out about the person's local community resources and explores further afield for opportunities and activities that are relevant for what matters to the person. This could be evidenced in personal planning documentation and feedback from individuals on their experience of PDS.
h.	The PDS practitioner has an understanding of rehabilitation needs and practical interventions that can make a difference in the home environment such as Occupational Therapy Home Based Memory Rehabilitation, local Care and Repair Service, access to the internet and IT equipment to connect with services and others, and supports the person to access these where available. Feedback from individuals on their experience of PDS.
i.	The PDS practitioner is able to direct the person to advice on driving and dementia and to assisted travel options. Useful information can be found on Alzheimer Scotland's website[19]. For assisted travel search for links such as: • Scotrail (www.scotrail.co.uk/form/assisted-travel), or • First (www.firstgroup.com/bus-accessibility).
j.	The PDS practitioner is confident in using technology such as Near Me (www.nearme.scot) to connect virtually with people and can access support to enable them to do so. The practitioner also has an understanding of: • ADAM (www.meetadam.co.uk) • the Virtual Resource Centre (www.alzscot.org/vrcpreview), and • assistive technology and *Dementia Circle* recommended products (www.alzscot.org/living-with-dementia/staying-independent/useful-products). Training records may show attendance at assistive technology sessions. Contact Alzheimer Scotland for advice on digital solutions digital@alzscot.org. Personal planning documentation records the person's consent to present or future use of such technology and any support required to use this. Feedback from individuals on their experience of PDS.
k.	Support and supervision format allows for reflection on personal outcomes-focused approaches and includes caseload supervision. Support and supervision records and dates.

2. I am confident in the people who support me following my diagnosis

Quality criteria	Suggested evidence
l.	The PDS practitioner attends team meetings, PDS practitioner network events, is a member of Focus on Dementia's practitioner network and receives and contributes to the newsletter. There is a reasonable level of administrative support to assist the PDS practitioner.
m.	The PDS practitioner informs other health and social care and housing providers in their area, who support or come into contact with people with dementia, of the existence of PDS and the service that can be provided. Consider, for example, if GP practices have been informed that the service is available, give them information leaflets and a key contact. With the person's permission, inform services who support the person of any PDS input. It is important to know that housing providers have a Housing and Dementia Practice Framework[20] similar to this PDS framework. The housing framework includes criteria on PDS.
n.	The PDS practitioner has an understanding of Scotland's past and present national dementia strategies and the national commitment to delivering and improving post-diagnostic support and how their role fits with this. This could be asked as a question at interview, discussed at team meetings, at support and supervision, and at personal development reviews.

3. I know more about my dementia and have adjusted to my diagnosis	
Quality criteria	**Suggested evidence**
a.	The PDS practitioner has undertaken education on the different types of dementia and knows where to find information on rarer types of dementia. This could be evidenced through personal development plans, personal planning and feedback from individuals on their experience of PDS.
b.	Personal planning documentation records coping strategies. If self-management is no longer viable for the person then evidence may be about the support others receive to support the person with the changes taking place. Personal planning documentation also records strategies for keeping as safe as possible for example planning ahead with the use of Purple Alert[12] and the Herbert Protocol[11] if the person is, or could become, vulnerable to going missing. Personal planning should also pay attention to any support the person needs for their physical care, for example, keeping active and attending medical appointments including eye tests and dental appointments. Personal planning should also pay attention to any support the person needs for their physical care, for example, keeping active and attending medical appointments including eye tests and dental appointments. Research shows that cognitive impairment significantly lowers the odds of sight checks and dentist visits[21]. Feedback from individuals on how the PDS service is making a difference to coping abilities and physical health.
c.	Support planning may include information on carer education, information given to carers about dementia and coping strategies. Feedback from those who care for the person on how the PDS service is making a difference.
d.	Support planning can evidence offers and take up of peer support opportunities. For people who require support at the '8 Pillars level'[6], the person may be attending a day centre which can be a source of peer support. If the person is housebound then ability to access peer support may be limited, however the service may be able to evidence use of creative methods such as technology to help people connect with others. Feedback from individuals on how the PDS service is supporting them to meet others.
e.	Records of signposting and referring to other supports. Feedback from those who care for the person on how the PDS service is making a difference to them.

4. I feel listened to and what matters to me is at the heart of decisions about me	
Quality criteria	**Suggested evidence**
a.	Assessment, support planning and review notes clearly evidence that the person has agreed to the referral and has been involved in decision-making throughout. Where the person has lost the ability to engage with and understand the concept of PDS, making use of previous wishes, and carer/family input can be a source of evidencing that the person has still had an influence over their PDS. Feedback from individuals on their experience of PDS.
b.	Where the service is refused, notes evidence number of attempts to encourage the person to take up the support, and discussions with the carer, before the case is closed or referred on to another service. The case should not be closed at ‘first refusal’. It is common for the person with dementia to decline support when first offered. The PDS practitioner needs to be prepared for this and take time to build a relationship with the person and gain trust.
c.	Support planning and notes clearly evidence what is important to the person and those who care for them along with any other significant information that has informed decision-making. Feedback from the person and those who care for them on feeling listened to and supported.
d.	Support planning assessments evidence an asset-based approach whereby strengths and abilities are identified and what matters to the person is recorded along with any goals and wishes they may have. The service may also refer the person to other supports to maximise their abilities, for example to occupational therapy, physiotherapy and technology champions.
e.	Support planning assessments evidence an asset-based approach whereby the person’s existing hobbies and interests are identified, and strategies are in place to maintain these valued activities.
f.	Support planning assessments evidence an asset-based approach whereby the person’s community of choice and natural networks are identified, and strategies are in place to maintain these connections.
g.	Support qplanning assessments may identify communication needs and best approaches and/or the PDS practitioner knows where to access advice on the different approaches to supporting communication in dementia, for example speech and language therapy.
h.	Feedback from those who care for the person on feeling listened to and supported and how the PDS service is making a difference to them.

5. I feel better about the future knowing I have made plans

Quality criteria	Suggested evidence
a.	Evidence might include a record of any training or study the PDS practitioner has undertaken to equip them to discuss and support the person with future planning. Other evidence could be personal plans, Powers of Attorney, Anticipatory Care Plans, benefits claims, referrals to other agencies such as housing if the person's home may not suit them for much longer and a move could be considered.
b.	A personal plan can take many formats; there is not one set format or template for this. The plan may comprise several pieces of information, for example begin with a Getting to Know Me[18] document or music playlist, such as Playlist for Life[22], as an introduction to the concept of having a personal plan to assist with living well and future support and move on to documenting coping strategies, future wishes and anticipatory care planning. A service may have evidence of checking their personal planning practice against the Essential 5 Criteria[23] (see Appendix 3). Where people are unable to engage with the concept of a personal plan then the PDS practitioner could evidence reference to past wishes and carer input to inform the personal plan. What is important to the person and how they wish to live can still be discussed and added to any plans to best reflect the person's thoughts and wishes.
c.	Evidence of information given and/or support on benefits claims, support for setting up Powers of Attorney and/or self-directed support.
d.	Evidence that practitioners are aware of where to signpost people (for example, Alzheimer Scotland Dementia Research Centre) to if they enquire about participating in research, a common one being about donating brain tissue to research following the person's death[24].
e.	Evidence that information, relevant for the individual's KIS[f] held by the GP, has been passed on where appropriate and with the person's consent. Relevant information would include PDS input and information from the individual's personal plan particularly if it includes anticipatory care planning details.

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[f] The KIS is a widely recognised tool with potential to share important information securely but widely across the system. KIS has been increasingly shown to have a strong link with good anticipatory care planning and palliative care[13].

Appendix 2: Post-diagnostic support improvement plan (example template)

Service name:		**Date**	
The top three priorities for improvement	**Lead?**	**By when?**	**Date completed**
Any other improvements	**Lead?**	**By when?**	**Date completed**

Appendix 3: Key policies, principles, rights and standards informing the delivery of high quality post-diagnostic support

Authors	Alzheimer Scotland, COSLA and Scottish Government
Title	Scotland's National Dementia Strategy 2017-2020
Available at	www.gov.scot/Resource/0052/00521773.pdf

The strategy maintains a focus on improving the quality of care for people living with dementia and their families through work on diagnosis, including post-diagnostic support; care co-ordination during the middle stage of dementia; end of life and palliative care; workforce development and capability; data and information; and research. Crucially, within this strategy, there is a recognition of the importance of taking a person-centred and flexible approach to providing support at all stages of the care journey.

Authors	Alzheimer Scotland
Title	5 Pillars Model of Post-Diagnostic Support
Available at	www.alzscot.org/campaigning/five_pillars

This model sets out how people newly diagnosed with dementia should be supported by a named professional delivering post-diagnostic support with respect to:

- Understanding the illness and managing the symptoms
- Supporting community connections
- Planning for future care
- Planning for future decision-making, and
- Peer support.

<table>
<tr><td>Authors</td><td>Alzheimer Scotland</td></tr>
<tr><td>Title</td><td>8 Pillars Model of Community Support</td></tr>
<tr><td>Available at</td><td>www.alzscot.org/campaigning/eight_pillars_model_of_community_support</td></tr>
<tr><td colspan="2">This model sets out a comprehensive and evidence-based approach to the integrated support of people with dementia living at home or a homely setting during the moderate to severe stages of the illness.</td></tr>
</table>

<table>
<tr><td>Authors</td><td>Alzheimer Scotland</td></tr>
<tr><td>Title</td><td>Connecting People, Connecting Support</td></tr>
<tr><td>Available at</td><td>www.alzscot.org/ahp</td></tr>
<tr><td colspan="2">This framework is about AHPs in Scotland maximising their contribution to supporting people with dementia and their families, partners and carers to live positive fulfilling and independent lives. It features as one of the key commitments outlined in Scotland’s third National Dementia Strategy (2017-2020) and the Dementia and COVID-19 - National Action Plan.
In 2021, a new resource ‘Connecting you to support – practical advice by AHPs’ was published. The resource was developed by Allied Health Professionals in Lanarkshire. The resource aims to provide practical advice to support people to live well with dementia. Further helpful evidence based self-management resources are available at www.alzscot.org/ahpresources</td></tr>
</table>

<table>
<tr><td>Authors</td><td>Alzheimer Scotland</td></tr>
<tr><td>Title</td><td>Dementia - Money and Legal Matters: a Guide - Volume 1 and 2</td></tr>
<tr><td>Available at</td><td>www.alzscot.org/assets/0000/0276/Dementia_-_Money_and_Legal_Matters_-_Vol_1.pdf
www.alzscot.org/assets/0000/0277/Dementia_-_Money_and_Legal_Matters_-_Vol_2.pdf</td></tr>
<tr><td colspan="2">A guide in two volumes which provides support to people with dementia and their carers on managing their money, planning ahead, arranging power of attorney, options for care, and eligibility for welfare and benefits.</td></tr>
</table>

Authors	Cross Party Group in the Scottish Parliament 2009
Title	Charter of Rights for People with Dementia and their Carers in Scotland
Available at	www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf

The charter is guided by a human rights-based approach (known as the **PANEL** approach, endorsed by the United Nations). It emphasises the rights of everyone as below.

- **P**articipate in decisions which affect their human rights.
- **A**ccountability of those responsible for the respect, protection and fulfilment of human rights.
- **N**on-discrimination and equality.
- **E**mpowerment to know their rights and how to claim them.
- **L**egality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.

Authors	Healthcare Improvement Scotland
Title	The Essential 5 Criteria Bundle
Available at	www.widgetlibrary.knowledge.scot.nhs.uk/media/WidgetFiles/1010348/Essential%205%20Bundle%20Guidance%20Final%20June%202015.pdf

This bundle clarifies the expected minimum level of personalised planning for the future care of people with dementia, supported by the designated post-diagnostic support practitioner delivering post-diagnostic support and involving carers, families and others close to the person. It is divided into the following five criteria:

- Person is at the centre of the plan
- Personal outcomes
- Person has ownership of the plan
- Personal resilience, and
- Plan is reviewed.

Authors	NHS Health Scotland and Alzheimer Scotland
Title	Dementia and Equality - meeting the challenge in Scotland
Available at	www.healthscotland.scot/media/1226/27797-dementia-and-equality_aug16_english.pdf

This report was compiled by the National Advisory Group on Dementia and Equality and provides recommendations for providing high quality support to everyone with dementia in Scotland. It lays out the following four themes:

- Continue to raise awareness
- Ensure robust services and support pathways
- Ensure appropriate knowledge and skills, and
- Research.

Three priority recommendations are also detailed for each of the following five population groups with characteristics protected by the Equality Act 2010, where challenges might arise in the context of dementia:

- Age – younger onset dementia (under the age of 65 years)
- Race and ethnicity – people with minority ethnic backgrounds
- Learning disabilities
- People / groups with a minority sexual orientation, and
- Disability – sensory impairment.

Authors	NHSScotland, The Scottish Government, Alzheimer Scotland, Scottish Fire and Rescue Service, Tunstall and Tynetec
Title	Technology Charter for People Living with Dementia in Scotland 2015
Available at	www.alzscot.org/assets/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf

The Technology Charter for People Living with Dementia in Scotland 2015 follows on from the Charter of Rights for People with Dementia and their Carers in Scotland (Cross Party Group in the Scottish Parliament 2009) and aims to support achievement of the National Health and Wellbeing Outcomes and the 20/20 Vision for Scotland. The Technology Charter for People Living with Dementia in Scotland 2015 is written to drive change and support the implementation of:

- Scotland’s National Dementia Strategies (2010, 2013, 2016 and onwards)
- Standards of Care for People with Dementia in Scotland (2011)
- Promoting Excellence (2011)
- Existing Models of Dementia Care and Support (Post-Diagnostic Support, 5 Pillars Model and 8 Pillars Model)
- Emerging, and future, nationally agreed Models of Dementia Care and Support
- National and local housing policies and strategies, and
- National Technology Enabled Care Programme workstreams.

Authors	Scottish Government
Title	Carers’ charter: Your rights as an adult carer or young carer in Scotland
Available at	www.gov.scot/Resource/0053/00533199.pdf

The Carers (Scotland) Act 2016 came into force on 1 April 2018. This act strengthened the rights of carers in Scotland and in particular, aims to improve their health and wellbeing.

This charter is designed to make carers aware of their rights under this act.

Authors	Scottish Government
Title	Health and Social Care Standards: My support, my life
Available at	www.gov.scot/Resource/0052/00520693.pdf
These Health and Social Care Standards set out what people should expect when using health, social care or social work services in Scotland. They seek to provide better outcomes for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to are upheld.	

Authors	Scottish Government
Title	Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy
Available at	www.gov.scot/Resource/Doc/350188/0117212.pdf
These standards set out the following rights for people with dementia. • I have the right to be regarded as a unique individual and to be treated with dignity and respect. • I have the right to access a range of treatment, care and supports. • I have the right to be as independent as possible and be included in my community. • I have the right to have carers who are well supported and educated about dementia. • I have the right to end of life care that respects my wishes.	

Authors	Scottish Social Services Council, NHS Education for Scotland
Title	Equal Partners in Care (EPiC): Practice guidance for working with carers and young carers
Available at	www.knowledge.scot.nhs.uk/media/6525404/epicare%20practice%20guide_final%20june%202013.pdf

EPiC is the national framework for workforce learning and development related to unpaid carers. It comprises of a set of core principles which are based on six outcomes for carers and young carers. The framework also has associated learning modules.

Authors	Scottish Social Services Council
Title	Personal Outcomes Planning
Available at	learningzone.workforcesolutions.sssc.uk.com/course/view.php?id=90%20-%20section-1

This is a useful resource for people working to put personal outcomes at the heart of what they do day to day. A personal outcomes approach:

- aims to shift engagement with people who use services away from service-led, input-orientated approaches by working towards specific outcomes identified by the person
- is used in assessment, planning, review and evaluation
- involves everyone working together to support the person to have the best quality of life possible, and
- involves the person in identifying and working towards his or her outcomes, which is critical to the approach and will support and promote individuals' independence, quality of life and well-being.

Authors	Scottish Social Services Council, NHS Education for Scotland and Scottish Government
Title	PROMOTING EXCELLENCE 2021: A framework for all health and social services staff working with people with dementia, their families and carers
Available at	www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/documents/
The framework sets out the knowledge and skills all health and social care staff should achieve in their roles in supporting people with dementia, their families and carers. It works alongside other standards and frameworks, such as the NHS Knowledge and Skills Framework, the Social Services Continuous Learning Framework and the National Occupational Standards for Health and Social Care. The framework also has relevance and applicability to other sectors, such as housing.	

Authors	Scottish Social Services Council and NHS Education for Scotland
Title	Promoting excellence in supporting people through a diagnosis of dementia
Available at	www.nes.scot.nhs.uk/media/nkifqsye/supporting_people_through_a_diagnosis_of_dementia.pdf
This 'enhanced practice' resource produced by NHS Education for Scotland (NES) advocates a personal outcomes-focused approach to supporting people with dementia and their carers before, during and following a diagnosis of dementia.	

Participation resources	
Authors	The Dementia Engagement and Empowerment Project
Title	Tips for organisations wanting to consult people with dementia about written documents
Available at	dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf
This guide provides tips for organisations wanting to consult with people with dementia about written documents.	

Authors	Healthcare Improvement Scotland Community Engagement
Title	Participation Toolkit
Available at	www.hisengage.scot/equipping-professionals/participation-toolkit/
This toolkit supports NHS staff to involve patients, carers and members of the public in their own care and in the design and delivery of local services. It offers a number of tried and tested tools along with some more recently developed approaches.	

Authors	Healthcare Improvement Scotland's Improvement Hub
Title	Anticipatory Care Plan Toolkit
Available at	ihub.scot/acp
This guidance has been developed to help health and social care professionals to support individuals who would benefit from Anticipatory Care Planning.	

Authors	Kate Allan, Joseph Rowntree Foundation
Title	Exploring Ways Staff Consult People with Dementia about Services
Available at	www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services
This paper, written by Kate Allan for the Joseph Rowntree Foundation, explores how staff can encourage people in their care to express their views and preferences. It describes how staff in ordinary settings were supported in developing individualised approaches to consultation, building on individual service users' personal strengths.	

Authors	Social Care Institute for Excellence
Title	Participation in development of dementia care
Available at	www.scie.org.uk/dementia/supporting-people-with-dementia/participation-in-development.asp
This video highlights how commissioners support organisations and carers and how they all have a role to play in enabling the person with dementia to share their knowledge and experience for the benefit of others and gives practical examples.	

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Published January 2022

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