The Post-Diagnostic Support Quality Improvement Framework

See [Appendix 1](#App1) 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** | | | |
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| **Quality criteria for the service** (how to support the above outcome) | **Yes** | **No** | **Evidence/Comments** |
| 1. Post-diagnostic support is offered, planned and delivered at a pace and in an order that reflects the person’s needs and assets. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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](https://www.scie.org.uk/dementia/support/technology)7. |  |  |  |
| 1. 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. |  |  |  |
| 1. Information about the service is provided in a language and format that is easy to understand. |  |  |  |
| 1. 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. The service is able to recognise the need for urgent post-diagnostic support and, if possible, can prioritise or fast track referrals. |  |  |  |
| 1. 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. |  |  |  |
| 1. The service has approved arrangements in place for sharing personal information appropriately. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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. 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** | | | |
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| **Quality criteria for the service** (how to support the above outcome) | **Yes** | **No** | **Evidence/Comments** |
| **The practitioner delivering post-diagnostic support:**   1. Has a clear remit and dedicated time and resources to carry out their role. |  |  |  |
| 1. 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. |  |  |  |
| 1. Has the key knowledge and skills to support the person and those who care for them as outlined in the Promoting Excellence resources8, 9 (see link in [Appendix 3](#App3)). This includes the ability to engage with the person via technology if the person chooses this as a preferred method. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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 makes10. |  |  |  |
| 1. Supports the person’s ability to keep in touch with contacts who can provide support. |  |  |  |
| 1. Informs the person and those who care for them about available activities, opportunities and online resources and, where required, supports access to these. |  |  |  |
| 1. 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. |  |  |  |
| 1. Can access advice on driving and assisted travel options. |  |  |  |
| 1. 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. |  |  |  |
| 1. Receives regular support and supervision which allows for reflection on personal outcomes-focused approaches and supervision of caseload. |  |  |  |
| 1. Has access to peer support networks, post-diagnostic support resources and appropriate administrative support to keep administrative tasks to a minimum. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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** | | | |
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| **Quality criteria for the service** (how to support the above outcome) | **Yes** | **No** | **Evidence/Comments** |
| 1. 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. |  |  |  |
| 1. 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](https://www.scotland.police.uk/what-s-happening/missing-persons/the-herbert-protocol/)11 and [Purple Alert](https://www.alzscot.org/purplealert)12. |  |  |  |
| 1. 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. |  |  |  |
| 1. The person has access to peer support. |  |  |  |
| 1. 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** | | | |
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| **Quality criteria for the service** (how to support the above outcome) | **Yes** | **No** | **Evidence/Comments** |
| 1. 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. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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. |  |  |  |
| 1. The person is empowered and enabled to make the most of their strengths and achieve what matters to them. |  |  |  |
| 1. The person is supported to continue to be included in their community. |  |  |  |
| 1. The person is supported to maintain doing activities that are important to them. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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** | | | |
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| **Quality criteria for the service** (how to support the above outcome) | **Yes** | **No** | **Evidence/Comments** |
| 1. 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. |  |  |  |
| 1. 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. |  |  |  |
| 1. 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. |  |  |  |
| 1. The person is supported to find out how to participate in research if this is something they wish to do. |  |  |  |
| 1. 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** | |
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| **Quality criteria** | **Suggested evidence** |
|  | 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](#App3) for resources to learn more about personal outcomes and outcomes-focused conversations.  Feedback from individuals on their experience of post-diagnostic support. |
|  | 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. |
|  | The service can demonstrate that it has considered and approved arrangements for using technology to connect with individuals and follows best practice principles7 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. |
|  | 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](http://www.dementiavoices.org.uk/wp-content/uploads/2021/03/LGBT-Dementia-Toolkit.pdf)), and * accessing translation services and producing anonymised case studies.   Note: The Public Health Scotland PDS dataset includes recording of equality data. |
|  | The service leaflet/information meets best practice guidance for written literature for people with dementia, for example see the [DEEP Guide - Writing dementia-friendly information14](http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf).  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. |
|  | 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. |
|  | 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. |
|  | 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](https://ihub.scot/improvement-programmes/focus-on-dementia/care-co-ordination/)15. |
|  | The service adheres to strict information governance protocols; data protection is included in policy and procedures and covered in staff training. |
|  | 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. |
|  | 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](https://www.alzscot.org/ahpdementia)16, to [Connecting you to Support](https://www.alzscot.org/sites/default/files/2021-09/AHP%20PDS%20Resource%20WEB.pdf)17 in [Appendix 3](#App3) and helpful evidence based self-management resources at [www.alzscot.org/ahpresources](http://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. |
|  | 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-diagnostic support’ booklet’.* The booklet can be viewed at the [ihub website](https://ihub.scot/media/6939/making-the-most-of-your-entitlement.pdf)[[1]](#footnote-1) and order free copies from [info@alzscot.org](mailto:info@alzscot.org). A [case study](https://ihub.scot/media/8809/using-the-making-the-most-of-your-pds-guide-to-support-delivery-of-pds-in-fife.pdf)[[2]](#footnote-2) 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. |
|  | If the person leaves the service the reason is recorded in their file and in Public Health Scotland data reporting. |
|  | 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. |

| **2. I am confident in the people who support me following my diagnosis** | |
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| **Quality criteria** | **Suggested evidence** |
|  | 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. |
|  | 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](https://www.alzscot.org/sites/default/files/images/0002/7225/Getting_to_know_me_form_-_editable.pdf)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 support6. 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. |
|  | 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](https://www.nes.scot.nhs.uk/media/nkifqsye/supporting_people_through_a_diagnosis_of_dementia.pdf)9.  Feedback from individuals on their experience of PDS. |
|  | 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. |
|  | 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 PDS10. |
|  | 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. |
|  | 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. |
|  | 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. |
|  | 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](https://www.alzscot.org/our-work/dementia-support/information-sheets/driving-and-dementia)19.  For assisted travel search for links such as:  Scotrail ([www.scotrail.co.uk/form/assisted-travel](https://www.scotrail.co.uk/form/assisted-travel)), or  First ([www.firstgroup.com/bus-accessibility](https://www.firstgroup.com/bus-accessibility)). |
|  | The PDS practitioner is confident in using technology such as Near Me ([www.nearme.scot](https://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](http://www.meetadam.co.uk)) * the Virtual Resource Centre ([www.alzscot.org/vrcpreview](https://www.alzscot.org/vrcpreview)), and * assistive technology and *Dementia Circle* recommended products ([www.alzscot.org/living-with-dementia/staying-independent/useful-products](http://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](mailto: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. |
|  | Support and supervision format allows for reflection on personal outcomes-focused approaches and includes caseload supervision.  Support and supervision records and dates. |
|  | 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. |
|  | 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](https://ihub.scot/improvement-programmes/housing-homelessness-and-healthcare/housing-and-dementia/)20 similar to this PDS framework. The housing framework includes criteria on PDS. |
|  | 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** | |
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| **Quality criteria** | **Suggested evidence** |
|  | 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. |
|  | 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](https://www.alzscot.org/purplealert)12 and the [Herbert Protocol](https://www.scotland.police.uk/what-s-happening/missing-persons/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 visits21.  Feedback from individuals on how the PDS service is making a difference to coping abilities and physical health. |
|  | 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. |
|  | 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. |
|  | 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** | |
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| **Quality criteria** | **Suggested evidence** |
|  | 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. |
|  | 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. |
|  | 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. |
|  | 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. |
|  | 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. |
|  | 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. |
|  | 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. |
|  | 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. |

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| **5. I feel better about the future knowing I have made plans** | |
| **Quality criteria** | **Suggested evidence** |
|  | 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. |
|  | 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](https://www.alzscot.org/assets/0002/7225/Getting_to_know_me_form_-_editable.pdf)18 document or music playlist, such as [Playlist for Life](https://www.playlistforlife.org.uk/what-is-a-playlist)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](http://www.widgetlibrary.knowledge.scot.nhs.uk/media/WidgetFiles/1010348/Essential%205%20Bundle%20Guidance%20Final%20June%202015.pdf)23 (see [Appendix 3](#App3)).  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. |
|  | Evidence of information given and/or support on benefits claims, support for setting up Powers of Attorney and/or self-directed support. |
|  | Evidence that practitioners are aware of where to signpost people (for example, [Alzheimer Scotland Dementia Research Centre](https://www.alzscotdrc.ed.ac.uk/)) to if they enquire about participating in research, a common one being about donating brain tissue to research following the person’s death24. |
|  | Evidence that information, relevant for the individual’s KIS[[3]](#footnote-3) 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. |

1. [ihub.scot/media/6939/making-the-most-of-your-entitlement.pdf](https://ihub.scot/media/6939/making-the-most-of-your-entitlement.pdf) [↑](#footnote-ref-1)
2. [ihub.scot/media/8809/using-the-making-the-most-of-your-pds-guide-to-support-delivery-of-pds-in-fife.pdf](https://ihub.scot/media/8809/using-the-making-the-most-of-your-pds-guide-to-support-delivery-of-pds-in-fife.pdf) [↑](#footnote-ref-2)
3. 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 care13. [↑](#footnote-ref-3)