

# All Wales Dementia Care Pathway of Standards

High Level Standard Descriptors

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## All Wales Dementia Care Pathway of Standards

The standards for dementia care have been scoped over the past two years with over 1800 people ranging from people living with dementia to voluntary sector organisations to practitioners across Wales and the UK.

This work has been led by Improvement Cymru as part of the Dementia Care Programme and directed by the requirements of the Dementia Action Plan for Wales, overseen by the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG).

There are twenty standards narrowed down from over one hundred potential standards and they drill down to the detail of what people believe will make a positive difference to dementia care in Wales. They are designed to be dynamic and by responding to evaluation and supporting evidence, standards can be added or subtracted. The twenty standards sit within four themes:

Accessible, Responsive, Journey, Partnerships & Relationships underpinned by <u>Kindness & Understanding</u>

The standards have been developed using the Improvement Cymru Delivery Framework. Part of this work has involved developing a two year Delivery Framework for the regions across Wales to cover the period 2021 – 2023.

This Delivery Framework will assist the regions in adopting and implementing the standards by offering support and assistance in year one to undertake engagement, coproduction, scoping, readiness and self-assessment. Year two will focus on implementing the standards into practice.

The standards are person centred and provide a proactive approach to meet each person's language needs. For Welsh speakers, the Active Offer is used to provide services that meet their language needs as a natural part of their care and to ensure relevant patients and carers are truly involved, and receive the best possible care and treatment.

Helping people from all communities to engage and get the support they need, for example people from different cultures and backgrounds such as Black, Asian, and minority ethnic groups.



4 Themes 20 standards wrapped around the person





## Introduction to the standard descriptors

- The standards have been prioritised from over 100 that could have been developed to the 20 described here
- The standards are dynamic, not static, meaning the set of standards will be evolving, when each standard is achieved across Wales it can be replaced with a new one. This means following a robust review standards can be added and subtracted
- There is a brief rationale provided to support understanding the context and evidence for each standard
- Each standard applies to all people being assessed, diagnosed and living with dementia and their carers recognising dementia as a vulnerable group, together with individuals with special characteristics such as Learning Disability, Black Asian and Minority Ethnic groups
- Regions should consider the standards in their entirety as they align with each other

- Identifying the high level responsibility for delivery will be included against the standards, however the key message is one of promoting partnership between agencies and stakeholders to drive the standards forward. At local level the Regional Partnership Board (RPB) and Dementia Forum will decide what agencies have responsibility against the standards and what that responsibility entails e.g. what actions. However, the overriding approach is one of multi-agency responsibility
- Reporting and measurement requirements align to a range of existing audit and reporting streams such as the Royal College of Psychiatrists and Health Care Standards with additional measurement definitions developed as necessary. Reporting and measurement will commence during the implementation phase and will be the responsibility of the RPB and the dementia forum
- Standards support the Dementia Action Plan (DAP) by focusing on a defined set of interventions determined to improve dementia care and will take the DAP core items forward over the next two to three years. This will assist in laying the foundation of what the DAP will look like for the next 5 years and beyond

## **Accessible**

01.

**Phase One:** This standard is about community engagement using one locality within a region working in partnership, taking 6-12 months to engage with that community to learn, evidence, and analyse what people and agencies have identified it needs e.g. Identify 'what dementia care and intervention looks like around here.' This will produce a vision and growth (delivery) plan. \*\*Due to COVID19 there will have to be a strong emphasis on all means of contact type and service provision that will follow the national guidance.

**Phase Two - Year two onwards:** support and assistance will be provided as part of the two year delivery framework. Each region will focus on implementing the agreed vision and growth (delivery) plan in year two, with a focus on measurement and assurance.

The focus for this standard **emphasises the phase one** component:

- Identify one community in a region e.g. Cwmbran, Carmarthen. Working in partnership demonstrating real engagement and coproduction to develop a plan for what dementia care means to that community what it looks like create a community vision that includes meeting places, centres or hubs. Coproduction will be robust, meaningful, evidenced and this will be demonstrated throughout the initiative. Taking this time to engage will ensure that the planning will fit with the community's needs
- A physical place for connection may be provided or it may not this standard is about what the community states they need
- This meeting place, centre or hub will be accessible and offer a safe, friendly environment for people to go to and start a conversation about their cognitive health. This conversation may be about being forgetful, feeling lonely, feeling down, isolated, struggling with everyday living and stressors or could be a place for people with dementia, their carers and families who may be struggling day to day to access the right care and support. It will offer a place to connect with people, the community and services, to assist with maintaining and maximising skills to enable people to live with dementia
- This meeting place, centre or hub includes digital / telephone connection and access
  to offer information, support, advocacy, peer support, social and physical health
  interventions and assistance for people living with cognitive health difficulties including
  dementia as a point of access and intervention.

\*\*The resulting vision and implementation plan forms part of phase two for this standard

#### **Brief Rationale**

Through coproduction regions can be informed by intelligence from its users to improve the quality of services, better design services and pathways based on users' experiences and expertise.

Throughout the consultation people told us that they didn't know where to go when they started to struggle with their cognitive health. People told us that they were not ready to have a formal conversation with their GP when they first started to have cognitive difficulties. Community cognitive health centres will support a safe place and the first step to start the conversation about cognitive health difficulties.

Accessible integrated community cognitive health centres will provide a dual function in supporting individual care services for people experiencing cognitive health difficulties along with providing active health promotion services to improve the population health within the community. This standard aligns to all other standards within this pathway in creating 'how dementia care looks around here.'

Services at the points of contact will provide reasonable adjustments to care that is meeting the person's needs and personal preferences. This will include all people that access community and inpatient services, recognising that people with dementia are a vulnerable group.

- Reasonable adjustments include: translating information so that it's easily
  understandable, adapting appointment times and venues to enable access and
  engagement, ensuring Did Not Attend (DNA) is not because people cannot process and
  act on information provided.
- Recognising that there is a need to have accurate data about who this population is in each region will evidence a progressive action plan to work towards making reasonable adjustments for all people living with a dementia (connects with standard one, three, and eleven).

#### **Brief Rationale**

The Equality Act 2010 outlines that a person has a disability if the person has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities. This Act recognises dementia as a disability under these terms and therefore, reasonable adjustments need to be made for all people who are living with dementia based on their individual needs.

Person-centred reasonable adjustments will support the person to live well by maximising their independence and ability to participate in their communities.

Article 5 of the Human Rights Act (1997) notes the importance of making sure that the most and least vulnerable people in our care are treated equally and that reasonable adjustments are made to ensure that all people can make informed decisions. This may include ensuring appropriate use of advocacy, ensuring the voice of the person is heard and appropriately responded to. For people subjected to Deprivation of Liberties Act safeguards, family and significant others (where appropriate) are informed.

This standard looks at the macro and micro level – how the care system responds to reasonable adjustments for all vulnerable groups, individualised approaches to support person-centred care and connects with standard one, asking do we have a robust implementation plan, a work stream for accessible information across all settings and a community.

- Memory Assessment Services (MAS) and Primary Care (GP) will adopt the READ
  Codes (coded clinical terminology thesaurus) to capture diagnosis of dementia and
  mild cognitive impairment and work together to promote early intervention and support
  (connects with standard one)
- Those diagnosed with dementia within settings outside of MAS (including primary care, community resource teams, psychiatric liaison and neurology) will provide the GP and MAS the specific READ Code within two weeks of a diagnosis
- MAS will evidence activity using the agreed data collection tool
- Regions will evidence increasing diagnostic rates by undertaking improvement cycles supported by the Increasing Diagnostic Rates resources when completed

#### **Brief Rationale**

Assurance is needed to ensure equity of service access and provision across Wales, no matter where a person is diagnosed, or what type of dementia diagnosis is given. MAS and primary care have access to the oversight of the diagnostic profile in their area. The mechanism to achieve standard three will be agreed locally as this will encourage partnership working to ensure that MAS and primary care are offering a partnership approach to all people and their carers, families with a diagnosis. Partnership arrangements will ensure that those only being seen by a GP will still be offered:

- Dementia coordinators or support workers
- Post diagnostic support, where necessary and signposting to post diagnostic support (cognitive centres could offer this intervention)

#### Wales can expect:

- an increase in the proportion of people with dementia receiving a formal diagnosis
- an increase in the proportion of people with dementia receiving a diagnosis when they are in the early stages of the illness
- an increase in the number of patients and carers who receive a positive experience of receiving cognitive health services
- reduced risk of crises later in the course of the illness.

The calculation of the estimated dementia diagnosis rate is described by StatsWales. Improvement Cymru and the National Wales Informatics Service(NWIS) are working jointly to develop the availability of monthly data as part of the MAS work stream and will also explore the breakdown of data e.g age range.

As part of the MAS work stream we are scoping the development of a dashboard that provides monthly updates on the estimated dementia diagnosis rate using GP registered populations to produce the denominator. This is further outlined in standard twenty and will be useful for supporting improvement in a more timely fashion.

Learning Disability (LD) services will define a process to capture the total population of people living with a learning disability and specifically Down Syndrome to offer a cognitive wellbeing check. This will include people known to all services including health, social and primary care services that include the GP and MAS. Learning Disability services are joined into the regional dementia care planning initiatives.

- Phase one: concentrate on Down Syndrome as the highest risk group
- Phase two: the wider population and those identified as at risk

#### **Brief Rationale**

People living with Down Syndrome are a high risk to develop dementia. It is widely recognised that early identification of symptoms that may indicate the onset of dementia, will enable the person to access an early diagnosis and thus, appropriate advice and support which will enable the person to live with dementia

#### Phase one:

- There will be an offer of a cognitive health wellbeing check at 30 years to ascertain a baseline assessment.
- A cognitive health wellbeing check will be offered to all people with Down Syndrome aged 40 years

This check will be provided by LD health services working with primary care, LD liaison and MAS in a joined up approach.

There are examples where a triangulation of data from primary care, LD health service and social care has taken place with good results in identifying people that potentially can have a cognitive wellbeing discussion. This improvement cycle will be used to scale and spread across regions.

This standard will support further work in identifying and reaching other populations such as BAME.

### Responsive

**05.** +

Health and social care services should provide the outcomes of an agreed set of completed assessment and interventions (listed) when referring to MAS (where the presenting need is indicated). This will assist MAS when they undertake assessments and in providing diagnosis. This will also support the person to manage any identified daily living difficulties.

#### **Brief Rationale**

There will need to be a joining of information and services to respond to this standard as per standard one. If information is already available use it, (connect MAS to other systems) if people have not had eye tests for years, suggest it and this links with population cluster work regarding the primary care response to aging and higher risk groups in how to engage them, get the basic interventions done, look at how people can be supported to attend opticians, audiology and the dentist etc. It is a whole systems approach.

Agreed set of completed assessments and intervention:

- Basic physical health tests as a baseline: BP / weight / height / routine blood tests
- Audiology referral / assessment / use of current hearing test (current equals within past two years unless difficulties identified)
- Dentist referral/ assessment / use of current oral health check (current equals annual unless difficulties identified)
- Ophthalmology referral / assessment (sight test) / use of current test (current equals annual unless difficulties identified)
- Cognitive Screening tools used by primary care for screening for cognitive health issues

#### **Medical History:**

- Social History routine history as a baseline of social support and connections
- Scans as appropriate as not all people will require a scan for cognitive health issues
- Activities of daily living profile to gather a baseline of everyday activities that the person currently participates in, is able to do and or also finding difficult

#### This standard:

- · Aids diagnosis in a timely manner
- Avoids diagnostic overshadowing avoids unnecessary referrals to MAS for assessment of cognitive health as it will pick up underlying predominant physical health needs
- Provides baseline for a number of functions which is important to measure deteriorate against going forward.
- Defines partnership arrangements, expectations and support
- Supports structured referral
- Promotes access to online investigations
- Encourages prudent practices

Where GPs are unable to offer items, an exploration of the support required to achieve this standard will take place. Partnership and positive relationship working between MAS and GP practices maybe key to achieving integrated streamlined services which are both cost and clinically beneficial to all stakeholders.

The key to this standard will be to determine the process for completion and who is responsible for delivery, including the person and their carers. A region will need to scope this and test it as per the delivery framework. MAS assessing a person presenting with a complex picture, therefore, need as much information as possible.

Memory Assessment Services, within a 12 week period from point of referral, will provide a range of interventions (listed) to support diagnosis. Digital platforms and other adaptions and approaches may need to be considered.

#### **Brief Rationale**

#### This standard:

- · Aids diagnosis in a timely manner
- Avoids diagnostic overshadowing by ruling out any underlying predominant physical health needs
- Addresses any underlying senses difficulties
- Ensures support and advice around emotional and psychological adjustment to diagnosis for the persons, carer and family
- Ensures support and advice around managing cognitive impairment and the effect this has in managing everyday living activities, roles and relationships
- Ensures a key person supports the individual, their carer and family through uncertain times when exploring whether the person has a terminal condition
- Supports various options for people living with dementia: a telephone contact, the named clinic contact, 3rd sector coordinators

MAS within a twelve week period from point of referral will provide:

- Activities of Daily Living Functional Skills Assessment
- Cognitive assessments: ACE-111 and MoCA
- Scans i.e. CT, PET (as appropriate for those identified)
- Physical health review using baseline information provided by primary care where appropriate as clinical need determines
- Assessment of carers needs and specific support related to adjusting to role and maintaining carers health and wellbeing
- Social history including social isolation assessment and signposting, accommodation and financial
- Emotional support during the assessment period and when providing a diagnosis
  provided by a practitioner or staff member that best knows the person, their carer and or
  family
- Pre diagnostic counselling offered
- Named contact: people receiving a cognitive health assessment will have a point
  of contact to discuss concerns, the process of assessment and potential outcomes
  throughout the assessment period
- Cognitive functional Interventions & Strategies (delivered in the home environment or other settings as appropriate to support everyday functional difficulties resulting from the cognitive impairment difficulties)
- Senses assessments (using baseline assessment provided by primary care as these may not be needed to be repeated within this twelve week period)

Physical health review within MAS: The purpose of the delivery framework is for a region to determine what they have already in practice and what they need to meet the standard. There are opportunities to work in partnership across agencies to meet areas such as physical health and also identify a gap in skills.

Cognitive interventions, strategies and post diagnosis intervention. It is assumed that intervention is not needed before diagnosis, when we know that it is important to take every opportunity to engage the person in strategies that can help them throughout the assessment period. This may help address some of the immediate issues they are facing e.g. functioning.

People will have access to a contact that can provide emotional support throughout the assessment period and over the next 48 hours after receiving a diagnosis and ensure following this period, it is offered as required.

#### **Brief Rationale**

During the consultation, we heard from people and their carers that they need support when going through the assessment period and when receiving a life changing, life limiting terminal diagnosis of dementia. Some of the experiences highlighted:

- Diagnosis can be given on a day when no core services are operating the following day
- Adjusting to this terminal diagnosis can potentially be devastating and traumatic to people and their families – appropriate support mechanisms need to be in place to support people through this period.

How we manage giving a life limiting diagnosis and the support that we give to help the person adjust to this, has been evidenced to show the impact on a person and their family's ability to make sense of what is happening and therefore, make appropriate lifestyle changes and plans for the future.

This standard offers the detail around the emotional support required during and post diagnosis and how we also manage giving a life limiting diagnosis to the person and their family.

08.

People living with Mild Cognitive Impairment (MCI) will be offered a choice of holistic services monitoring their physical, mental health and wellbeing, with reviews taking place as a minimum six monthly. This will include a range of options including peer support. Signposting and community resources should be at the centre of all intervention (connects to standard one and three).

#### **Brief Rationale**

Evidence suggests that 10-15% of people with a diagnosis of MCI develop dementia. Other studies have put this figure as low as 5-10% of people diagnosed with MCI will go on to develop dementia (Alzheimer's Research, January 2018).

For people diagnosed with MCI, early intervention approaches to monitor cognitive decline is important and advice around the six steps risk reduction messages will improve the understanding of health promotion and prevention activities to maximise their wellbeing.

There are a range of individual and group based physical activity interventions and opportunities within a community, that people can be signposted to or delivered by statuary and non-statuary services.

## Journey & Navigation

09.

Within 12 weeks of receiving a diagnosis, people living with dementia will be offered education and information on the importance of physical health activities to support and promote health. (connects to standard one).

#### **Brief Rationale**

People told us that that there is a lack of information about the importance of physical health promoting activites

There is an increasing evidence base to show that physical exercise interventions to improve strength, balance, mobility and endurance levels has a positive effect on preventing falls in older adults with cognitive impairment. Evidence also suggests that physical exercise experienced together can also have benefits for the person with dementia and their carer by maintaining and where able improving their physical, cognitive, social and emotional functioning, relationships and quality of life.

There are a range of individual and group based physical activity interventions and opportunities within a community that people can be signposted or delivered by statuary and non-statuary services.

MCI: A range of interventions and guidance for those diagnosed (with dementia and MCI) will be available as part of this standard and there will be access to interventions that are also tailored to meet the next steps for those diagnosed with MCI.



People living with dementia, carers and families will be offered learning, education and skills training. This offer will be stage appropriate and will be provided at significant parts of a person's journey. It will include a range of peer support and shared experience opportunities, (connects to standard one).

#### **Brief Rationale**

Receiving a dementia diagnosis and having the time and support to adjust to this diagnosis is very important. The individual may need support and advice on a number of key areas from friends, family, peers, experts by experience or with a health or social care professionals, or others in a field that understands dementia. Key areas of learning to support adjustment and living well may include information and advice on treatments and ways to stay active and healthy, financial matters and planning ahead, employment (if the person is still working), driving, practical, emotional and relationship support to live well.

Throughout the consultation people told us that learning and support opportunities must also be offered throughout the person's journey therefore, a chance to receive stage appropriate, needs appropriate information and skills sessions at the right time is important.

It is recognised that there should be a strong emphases for family and care partners to be included in all opportunities to ensure they can access the necessary support, advices, skills and information to perform their role. Cognitive functional interventions and strategies are to be included and there will be a national resource available that includes a range of programmes to acknowledge carer needs and skills.





Wales will adopt the Dementia Friendly Hospital Charter with a regular review of implementation and outcomes.

#### **Brief Rationale**

Principles for practice in the Dementia Friendly Charter reflect the aspirations in the Dementia Action Plan for Wales 2018-2022. These cover a number of person centred, rights based approaches including:

- Providing choice around meal times
- Letting people sleep and wake at their own pace
- Allowing flexible visiting times
- Ensuring that care and treatment is culturally sensitive and that where Welsh is a person's first language, care and treatment is provided in Welsh
- Facilitating families and carers to continue to support a person with dementia whilst they
  are in hospital if they wish
- Adapting environments so they are more 'dementia supportive' such as considering the layout and signage.

By establishing a Wales version of the Dementia Friendly Hospital Charter that is used in England will mean there is a clear focus for the development of robust dementia care provision.

Wales will take learning from the approach in England and build upon it by using a Regional Taskforce approach. This will ensure commitment from professionals, policy makers and people living with dementia and their carers. Having a taskforce in place to work with the region will help the sustainability of the work and regular meetings will ensure that the work continues.

There will be a readiness and self-evaluation tool supporting a peer review approach for care settings to gauge its own performance against the standards outlined in the Charter. Linking and sharing of practice will support equitability and quality improvement nationally, as well as creating and maintaining relationships with the Welsh health board regions.

The Charter aligns to key audit programmes such as health care standards and the Royal College of Psychiatry dementia hospital audit, plus others. Audit items have been cross referenced with the charter principles. It is important to use existing audits as supporting evidence against the charter, however, the focus of the charter will look at how the information is used locally to improve dementia care to meet the principles of the charter.

People living with dementia and their carers will have a named contact (connector) to offer support, advice and signposting, throughout their journey from diagnosis to end of life.

#### **Brief Rationale**

A named contact will ensure that people are connected to available local support networks, which may including peer support options, enable access to other financial and practical advice and information on what adjustments could be made to their lifestyle or environment to help them remain as fit and healthy as possible.

There will be a phased approach to meeting this standard:

#### Phase one:

This will include all newly diagnosed people with a dementia being provided with a named contact (connector)

#### Phase two:

Identify existing people diagnosed with dementia and provide a named contact (connector)

The dementia connector role will be defined nationally and it is the intention that the role function will help the person and carer to coordinate care. Many people diagnosed with dementia are not being seen by the core statutory dementia services however the function of this role must link with Social Service and Wellbeing Act (Wales) 2014 requirements of coordination and Mental Health (Wales) Measure 2010 care coordinator.



People living with dementia will have access, when needed, to relevant (and when accessing mental health services) dedicated services post diagnosis no matter their residence. This identifies with the care and team wrapped around the individual, (connects to standard one, three and twelve)

#### **Brief Rationale**

People in the consultation told us that despite accessing specialist mental health services like MAS, or secondary services there was limited access to a range of professional and voluntary groups working in partnership that can provide a range of treatment and intervention modalities.

Identified dedicated services include:

- Speech and Language Therapy
- Dietician
- Audiology
- Dentistry
- Ophthalmology
- Physiotherapy
- Palliative care from day of diagnosis
- Occupational Therapy
- Psychology
- Mental health nurses
- Social worker
- Mental health specialist services
- Podiatry

Every person's experience of their dementia will be unique. Dementia can affect people in many different ways and therefore a range of skills and professions are required to match people's needs. Dedicated services built around the individual will support timely access to address a range of needs so that the person can live well.

As an example: Community Resource Teams would be included in a team round the individual approach along with other services that people may need, including virtual means of engagement and face to face through a range of different approaches to connect e.g. how services work together as a one stop option within the agreed way that a local community has determined what dementia support looks like (as per standard one).

Dedicated services are services with the ability to respond to the needs of people with dementia and may not need to be dedicated staff working in dementia care within mental health services for example. The service e.g. community dietetics or physiotherapy has suitable funding to provide dementia care support within a community with an ability and resource to respond to need. This will mean core services scope what investment is needed to respond to dementia care as per the focus of standard one.

+

People living with dementia will have a current face to face appointment where a physical health review will be delivered in partnership by primary and secondary care. Where there is justifiable reason for not providing a face to face appointment, a physical health review will be delivered by other approaches i.e. digital platforms, telephone consultation.

#### **Brief Rationale**

People living with dementia are considered as a vulnerable group and therefore people with a dementia may be at risk of health and social inequalities. Health inequalities for people with a dementia can be exampled by the evidence that suggests people with dementia receive less primary, preventative healthcare than people without dementia.

Evidence suggests by increasing the numbers for health checks for people living with a dementia may improve health outcomes. There is also a direct associated with people receiving regular health checks needing fewer unplanned hospital admissions, (Cooper C, 2017).

Ensuring a health check becomes part of the annual care review for people living with a dementia will safeguard against any health inequalities that could potentially be experienced.

Partnership approaches to delivering the health checks maybe appropriate and would support the aim of care around the individual and provide easier access to care. Aligning with standard twenty and the measurement workbook, will capture how many people with a dementia received a face to face review to inform improvement.

15.

People within 12 weeks of being diagnosed with dementia will be offered support to commence planning for the future, including end of life care. This offer will include the opportunity to revisit and update this plan throughout the person's journey. Where appropriate, representation and the use of advocacy will ensure the rights of the person are upheld.

#### **Brief Rationale**

Planning for the future and making key decisions is important for every person as there maybe times when the person living with a dementia may not be able to communicate what is important to them, their wishes and needs in regards to daily living, health, social care, finance, housing and end of life decisions.

The important use of advocacy, when appropriate, during the consultation was strongly highlighted. This will ensure the rights of the person are upheld.

During the extensive scoping exercise for the standards, people described a need for support and introduction to support following diagnosis. People will know when they are ready to engage and will have had conversations about what needs to happen next. The consensus was: within a three month period, many people will be ready to engage acknowledging that there will be people who want to take longer or may never want to engage with future planning. This avoids the current situation of people receiving little support following diagnosis or support coming too late and the person cannot engage with their own planning.

Organisations and care settings providing intensive dementia care (this includes mental health and learning disabilities inpatient settings) will provide the framework and structure for Dementia Care Mapping (DCM) to become routine practice, supporting clinical reasoning and decision making. Mental health DCM services will offer DCM support to acute care, prisons and care homes settings.

#### **Brief Rationale**

Within the consultation, people told us that this was an important tool to evaluate and learn about person-centred enabling practice. By embedding this tool will help us to improve care across services. This tool will support evidence that ensures services are meeting and responding appropriately to people's needs at all stages of the person's journey. A DCM strategy for Wales will support this standard.

**17.** 

All staff delivering care at all levels within all disciplines and settings, will have the opportunity to participate in person centred learning and development with support to implement into daily practice. This will be a joint regional approach to identifying a range of learning and development opportunities including quality improvement.

#### **Brief Rationale**

The Good Work (2016) is a framework with the intention to support all people within all areas and stages of the dementia care field to be able to reflect and identify their individual person-centred learning development strengths and needs.

The effectiveness of any learning and development opportunities needs to be measured by the impact that it has had on care delivery not by the number of people that have been trained.

Understanding and incorporating improvement methodologies will support to provide the tools to evaluate and understand the detail and impact of learning and development opportunities on the outcomes of care delivered.

This standard supports the Goodwork Framework by detailing practical approaches and opportunities that can be classed as learning and development. It enhances the spirit of the framework moving from a set of criteria to practical application. What is classed as evidence of learning and development can be agreed and will therefore improve upon the basic reporting currently in place. It puts a responsibility on regions to focus on a range of learning and development opportunities including supervision.

People living with dementia, their carers and families will have support and assistance to engage with appointments. This will avoid receiving multiple health and social care appointments that can overwhelm, confuse and isolate the person.

- Reasonable adjustments to ensure coordinated effective offers are made to the person
- The organisation can review the offer of appointments and the way appointments happen e.g. digital technology, home visits, multidisciplinary review sessions, to ensure a coordinated response (connects with standard one, two and twelve)

#### **Brief Rationale**

Within the consultation, this was an area of frustration for people and carers. Practical streamlining of operational processes will support the service to avoid duplication and maximise opportunities to exercise prudent principles to service delivery. This may include exploring opportunities within roles, partnership working arrangements and developing integrated assessments, protocols and processes.

Access and appointments: A whole systems approach not just care coordination. Look at how the organisation / system supports vulnerable people and provides options for how people can access appointments when engaging with all settings and professionals across health and social care.

At a micro level, the person must have individualised reasonable adjustments made and this can be through and supported by care coordination, dementia connector roles and via team around the individual.



## Partnerships & Relationships

**19.** 

Services will ensure that when a person living with dementia has to change or move between any settings or services, care with supportive interventions will be appropriately coordinated to enable the person to consider and adapt to the changed environment. This will ensure that all care partners will communicate and work jointly with each other to support a seamless transition.

#### **Brief Rationale**

Transition includes a transfer of communication: care and support plans, intervention plans and 'Getting to know you' type documents. In this standard consider relationship building and partnership working to foster smooth transitions of care.

Ensuring that all services recognises and supports reasonable adjustments for both the individual and their carer during this time will improve the success of the person and their carer adapting and adjusting to change in their circumstances.

This standard is about the system of care being coordinated as well as making individual decisions. For example, avoiding numerous transfers between wards that can confuse and disorientate the person. This is a focus on system growth by reviewing, planning and implementation of how care can be delivered to the person, people with dementia at a systems and person level.

20.

Working in partnership, the region will deliver on the requirements of the agreed data items (measurement workbook) for reporting and assurance.

#### **Brief Rationale**

The collection of the agreed data items will provide an overview of the types of services and resources that are currently available to deliver dementia care. The standard will build upon existing items used for measurement within the regions and offer new items, where relevant. This will assist to detail a picture of the landscape of care that is being provided for people living with a dementia and their carers in Wales.

The extensive scoping exercise for the standards also consulted on measurement providing many examples of performance reporting not supporting practice. Usually reporting is undertaken without the purpose described to the workforce and therefore it becomes divorced from improvement in practice or data is asked for with short reporting turnaround times. This standard will offer a workbook approach – one workbook detailing all the requirements (with a rationale and definitions) provided on day one to the region and accessible to the workforce for that reporting year e.g. April 1st.

The workbook will detail all monthly, bi-monthly, quarterly, 6 monthly and annual reporting required highlighting what is needed to work towards etc. It will be part of the delivery framework for implementation in phase 2 and guidance will be provided for the regions on how to use the workbook.

Thank you to all the people across Wales and beyond involved in developing the dementia standard descriptors. Your passion, expertise, lived experience and commitment has enabled these high level descriptors to be developed in support of the forthcoming Dementia Pathway of Standards and Delivery Framework.





