West Wales Care Partnership (WWCP) Dementia Strategy

wwcp
Partneriaeth Gofal Gorllewin Cymru
West Wales Care Partnership

Attain
Improving health and wellbeing

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1. Background

Background

- The West Wales Care Partnership (WWCP) brings together organisations from the statutory, third and independent sectors with a remit of integrating and transforming health, care and support in the region.
- A statutory Regional Partnership Board oversees the work of the WWCP.
- A regional Dementia Steering Group sits underneath the RPB and comprises representation from across the Partnership. It provides a mechanism for developing a regional approach to caring for people living with dementia (PLWD) and their families. This Group worked closely with Attain in developing the draft Strategy and will have a key role in taking forward implementation of the next phases of work.
- Welsh Government provides funding through the Integrated Care Fund (ICF) to support the improvement of care and support for PLWD and their families, This funding is managed through the Dementia Steering Group and will be instrumental in delivering agreed priorities within the Strategy.
- Key partners on the WWCP are:

Carmarthenshire Association of Voluntary Services

Pembrokeshire Association of Voluntary Services

Ceredigion Association of Voluntary Organisations

Hywel Dda University Health Board

Pembrokeshire County Council

Carmarthenshire County Council

Ceredigion County Council

Background

In February 2021, the WWCP appointed Attain to work with partners to develop a regional dementia strategy and service model pathway of care. Alongside this work, we carried out a review of the regional ICF dementia projects which provided a steer as to what services should continue to be funded, as well as an indication of any additional initiatives that should be undertaken during 2021/22. One priority area was for Attain to develop a business case for the introduction of a dementia wellbeing connector which is based on best practice and an intrinsic role within the WW Dementia Wellbeing Pathway.

The context for this work includes:

- Increasing focus worldwide on dementia and its impact on health and social care systems; prevalence is increasing year on year, mainly due to people living longer, particularly in high income economies.
- To clarify its dementia strategy, In February 2018, the Welsh government published the 'Dementia Action Plan 2018-2022'.
- The vision is for Wales to be a 'dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities'.
- In March 2021, Improvement Cymru published the All-Wales Dementia Care Pathway of Standards. This work, directed by the requirements of the Dementia Action Plan for Wales, is overseen by the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG).
- The twenty standards have been designed to be dynamic by responding to evaluation and supporting evidence. They sit within four themes: **Accessible, Responsive, Journey, Partnerships and Relationships Underpinned by Kindness and Understanding.**
- The standards have been developed using the Improvement Cymru Delivery Framework and it is anticipated that work will focus on developing a two-year Delivery Framework Guide for the Welsh regions covering the period April 2021 – March 2023.

Prior to the implementation of the Framework, Attain has co-designed this strategy with colleagues, people living with dementia and their carers across West Wales. The high-level strategy also provides a programme governance structure and the foundation on which to fund services which is in line with the Improvement Cymru Delivery Framework.

Project requirements and activities

This slide outlines the project requirements, the outcomes from the work undertaken and key actions.

The Ask:

1. Overarching Dementia Strategy and Delivery Plan

- Facilitate co-production of a regional dementia strategy with stakeholders, PLWD and their carers
- **Develop a sustainable model and associated delivery plan for the strategy in the medium to longer term,** deployment of existing and future funding streams to support this and accounting to Welsh Government and other stakeholders on delivery and impact
- **Consider future regional programme ownership** and leadership requirements to implement and deliver the dementia strategy
- The dementia strategy and associated delivery plan needs to be considered in the context of **changing demographics across the region**, the long-term impact of COVID-19 on people with dementia and evidenced impact of existing workstreams

2. Development of a business case for the dementia case manager role

- In line with All Wales dementia standards and the Health Board's recently developed palliative and end of life care strategy, develop a business case for the dementia case manager role

3. In respect of the above tasks, Attain have been required to:

- Work with a range of national and regional stakeholders, including Welsh Government officials, system leaders, service managers, clinicians and practitioners, elected and independent members and users and carers as appropriate
- Produce high quality proposals and reports to a range of audiences

Attain have:

1. Overarching Dementia Strategy and Delivery Plan:

- Produced a report following a review of national and international best practice
- Worked with colleagues to develop a **regional strategy, vision and service model pathway based on best practice**
- This strategy includes a **proposed programme and governance structure** which fits with the Welsh Government and Regional structures
- The strategy includes a summary of **current and future population demand and prevalence**. Information relating to the impact of COVID-19 upon those with dementia is not available at this stage
- Stakeholders have identified that COVID-19 has impacted timely diagnosis due to late presentations and inability to access assessment services

2. Development of a business case for the dementia wellbeing connector role:

- Carried out a desktop review on best practice in dementia case co-ordination/management and average case load level
- Developed a business case with input from the WWCP dementia steering group members

3. Stakeholder engagement:

- Attain have worked with multiple stakeholders across the region people living with dementia (PLWD) and their carers and front line staff. All West Wales Care Partners have been fully engaged and very supportive in the development of this strategy

Key Recommendations

1. Implementation of strategy and dementia wellbeing pathway

- Once the strategy is formally approved by the WWCP, socialise the recommendations of the strategy, and the dementia wellbeing pathway to ensure that it is owned by colleagues, PLWD and their carers across West Wales
- A communication plan should be developed to run for the life of the strategy
- WWCP to adopt the proposed governance structure and recruit a Regional Dementia programme manager
- A full business case should be developed to take forward the establishment of the dementia wellbeing connector role
- The strategy, vision and service model pathway should be reviewed once information is available regarding the impact of COVID-19 upon those with dementia and their carers
- The waiting time for diagnosis should be reviewed and monitored; solutions should be found to address long waiting times, including the codesign and development of the regional dementia diagnosis pathway

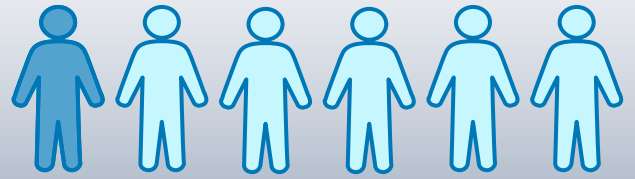
2. ICF Dementia Plan:

- The strategy recommends that a review be undertaken of ALL initiatives currently funded by the ICF, including evidencing outcomes, align funding to implement the strategic priorities, and ensure any new way of working is fully resourced
- Develop a regional strategic and co-ordinated approach to supporting carers – consider top slicing the dementia ICF funding to enhance the carers' element so ensuring continuation of services, supporting those who are caring for people living with dementia

2. Population needs analysis

For more information on the population analysis please see appendix 1

Population projection of those with dementia in West Wales



1 in 6

Alzheimer's Society UK estimates dementia affects one in six people aged 80+. West Wales records show 1 in 10 people over 85 with dementia.

Alzheimer's Research estimates that the diagnosis rate* is 53% across Wales, suggesting a **current** unmet need across Hywel Dda of 2,400 patients

The table below shows ALL diagnoses of dementia on the West Wales GP register **forecasted forward**, factoring in the increase in over 85s and an estimate of undiagnosed need. Data on waiting lists was not available but it is important to find ways to monitor this as demand increases.

County	Current diagnosed (on GP register)	Current estimated undiagnosed	Current estimated total prevalence	2040 projected diagnosed** (based on current diagnosis rate)	2040 projected undiagnosed**	2040 projected total prevalence
Carmarthenshire	1,363	1,208	2.571	2,035	1,793	3,828
Ceredigion	578	512	1,090	863	760	1,623
Pembrokeshire	871	772	1,643	1,300	1,145	2,445
West Wales	**2,812**	**2,492**	**5,304**	**4,198**	**3,698**	**7,896**

7,896 by 2040 (inc. undiagnosed need)

To put this into perspective…

This is equivalent to everyone in **Pembroke** living with dementia.

*The diagnosis rate is the diagnosis percentage compared to the estimated actual prevalence

** projection is based on the diagnosis rate remaining the same as current, this is a strictly 'Do Nothing' scenario

Dementia Diagnosis West Wales

Predominantly **(62%) female** due in part to longer life expectancy of women

65% of dementia patients in UK are women and they also make **up over 60% of carers**

45% of patients are over 85 years old and this population will grow across Hywel Dda

Leading cause of death in the UK (pre-COVID-19) and represents 12.7% of all deaths

Diagnosis prevalence across **Ceredigion is highest**: 0.8% of total list

Ceredigion has the highest proportion of **over 65s at 26%;** the average for Hywel Dda is 25%

The population of Hywel Dda is ageing, **over 10% will be over 85 by 2040**

Adult population is reducing across all areas, in particular in **Ceredigion (-11% 2040)**

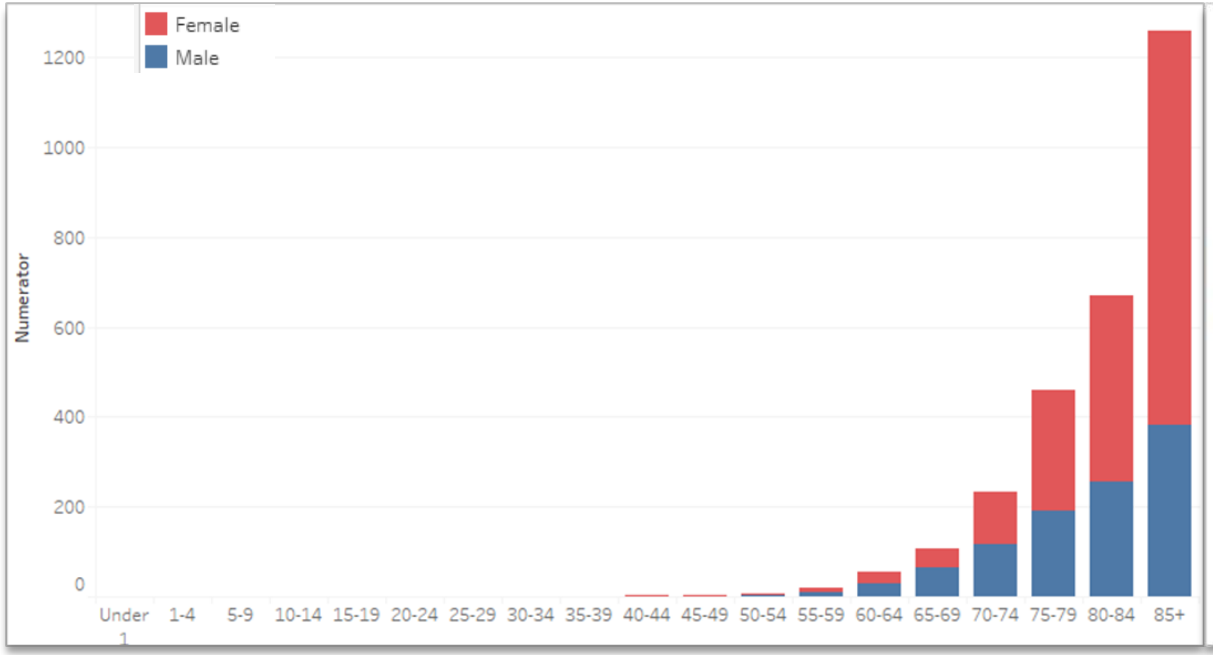
Decreasing adult population reduces supportive care for the older population

84 patients on the register with young onset dementia (0.06% of adults)

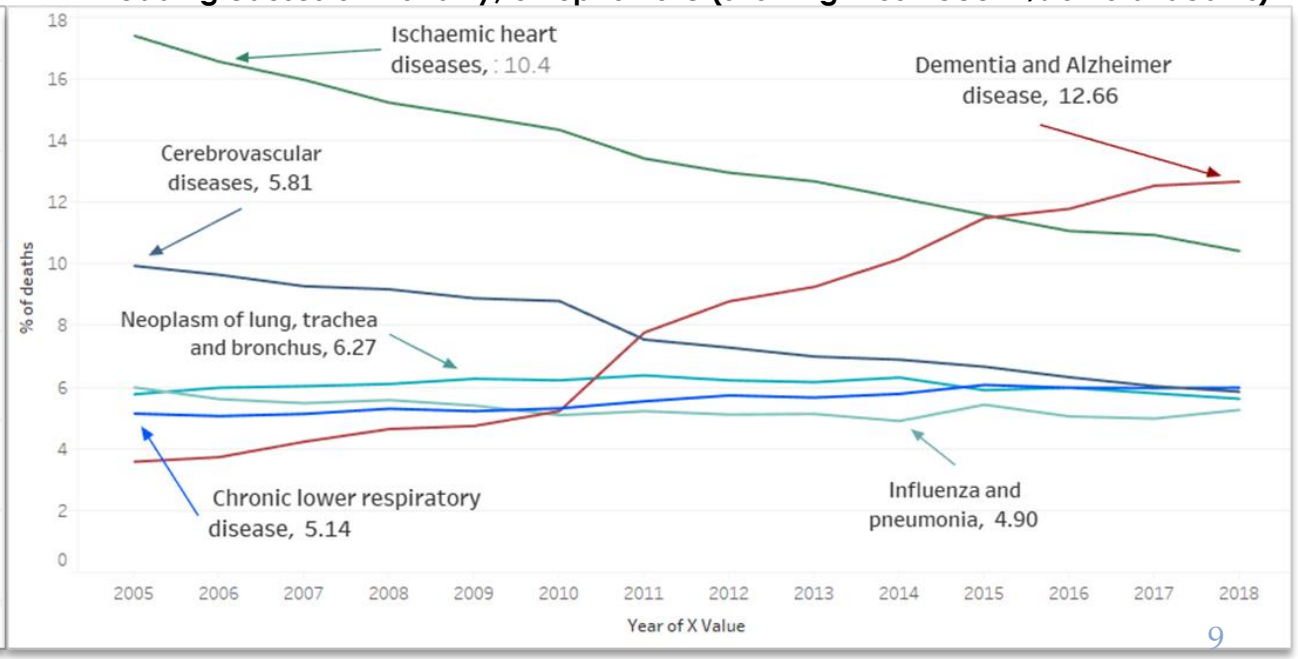
56% of young onset* diagnosis **are male** (24 are in Carms and 10 in Ceredigion)

*Young onset dementia is the onset of dementia when a person is under 65 years old. Across West Wales there are 84 patients on the registers who are under 65 years old. Of those, 55 are in the 60-65 year age group. This gives West Wales a rate of 0.04% across the population in the adult population, which is very similar to the rate seen across Wales registers nationally.

Patients on GP registers with a dementia diagnosis West Wales



Leading causes of mortality, UK up to 2018 (showing most recent % of total deaths)

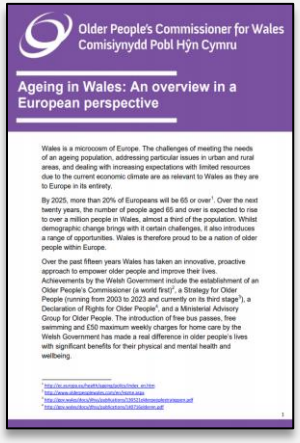


3. Current action plans, regional transformation projects

Relevant dementia documents for Wales:

This strategy and the future palliative & EoLC programme will draw on key existing initiatives:

Ageing Well in Wales



Launched in 2014 Ageing in Wales: An overview in a European perspective

5 Priority areas to Improve the health and well-being of older people in Wales :

- Age friendly communities
- Dementia supportive communities
- Falls prevention
- Loneliness and isolation
- Opportunities for learning and employment

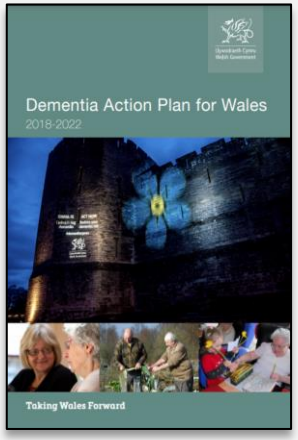
Appropriate accommodation for older people can help to contribute to addressing all of the above.

Good Work Framework A Dementia Learning and Development Framework for Wales

Published in 2016 Overall, the aim of the Framework is to support people to freely, creatively and responsibly identify and address their own specific learning and development needs within the context of their lives and circumstances, wherever they happen to be. The intention of the Framework is not to constrain people by providing an overly prescriptive list of who needs to know and do what.

This Framework is intended to support what matters most to the people of Wales, as well as the spirit and requirements of Welsh policy, legislation and guidance regarding the care, support and empowerment of people with dementia, carers and the health and social care workforce.

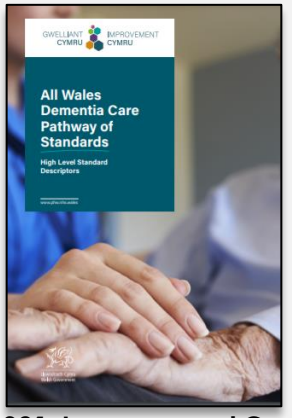
All Wales dementia action plan



In February 2018 the Welsh government published the 'Dementia Action Plan 2018-2022'

The Action Plan sets out a clear strategy for Wales to be a 'dementia friendly nation that recognises the rights of people living with dementia to feel valued and to live as independently as possible in their communities'.

All-Wales Dementia Care Pathway of Standards



In March 2021, Improvement Cymru published the All-Wales Dementia Care Pathway of Standards. This work, directed by the requirements of the Dementia Action Plan for Wales, is overseen by the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG).

20 standards have been designed to be dynamic by responding to evaluation and supporting evidence. They sit within four themes: **Accessible, Responsive, Journey, Partnerships and Relationships Underpinned by Kindness and Understanding.**

The standards have been developed using the Improvement Cymru Delivery Framework and the work will focus on developing a two-year Delivery Framework Guide for the regions across Wales covering the period April 2021 – March 2023.

EoLC Health Board dementia specific provision - West Wales area

The HDuHB Together for Health End of Life and Palliative Care Delivery Plan 2016 -2020 outlines the current EoLC resources available to support people with dementia: Source: HDuHB Together for Health End of Life & Palliative Care Delivery Plan 2016 -2020

Current Services:

- Using Welsh Government funding which was facilitated by West Wales Care Partnership, HDUHB commissioned Paul Sartori and Marie Curie to deliver training on Advance Care Planning and Dementia
- Marie Curie Senior Nurses help patients with advanced dementia access palliative and end of life care services across the region. The nurses support multi-disciplinary teams to meet the care needs of people with dementia in hospital, at home and in care homes. They also aid the safe transfer of care across care settings.
- Paul Sartori Foundation also provide education to a variety of audiences, both to their own staff but also to others across the Health Board, including topics such as dementia.
- In Pembrokeshire various members of the team have also contributed to other educational events, including teaching about Advance Care Planning at a dementia conference.

Areas for improvement:

- More work is needed on early detection of those living with dementia and to provide the support required. This will include education for colleagues within primary care to consider when someone with dementia is approaching their end of life and support to include this group within palliative care registers.
- Improve early detection and care of frail people accessing services, including those with dementia, specifically aimed at maintaining wellbeing and independence.
- Recognise the need to give particular focus to the experience of specific groups including those who have learning disabilities, dementia, hearing or sight problems and those who are elderly and frail. Carers are a particular group of people who often go unrecognised.
- In addition to the development of the Long-Term Care Patient Pathway, each Long-Term Care Specialist Nurse is developing a special interest in a particular area of expertise; these areas include pain management, end of life care, dementia care, nutrition, medication management and other aspects of fundamental care. These skills will be utilised to support safe and person-centred care delivery.

While services are in place in West Wales, implementing the priorities from the Welsh Dementia Action plan have been included in the palliative and EoLC programme plan and will have significant impact on the quality of EoLC services for those with dementia.

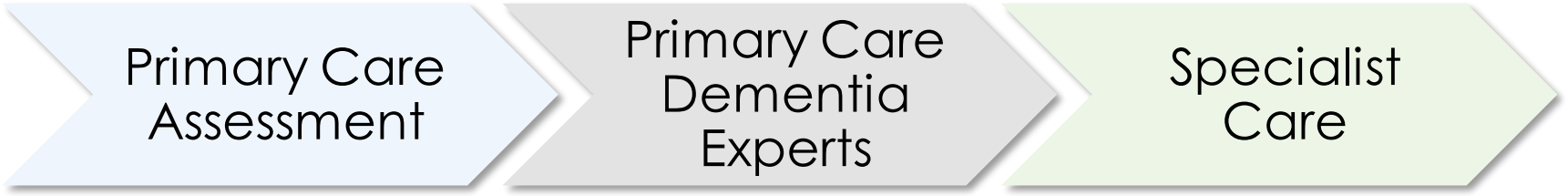
4. What does best practice tell us?

Dementia – key areas of focus

- The review of national and international best practice and innovation in dementia, identified many areas of best practice, research and innovation across the whole dementia care spectrum.
- Dementia is a condition that cuts across system wide services and is therefore everyone's business. It is important to understand to recognise that dementia services need to be embedded in the whole system of provision.
- This strategy focuses on key areas to drive improvement and innovation across West Wales, namely:
    1. Implementing strategies to achieve early diagnosis
        i. Supporting GPs, allied health professionals (AHPs) and nurses to make assessments and improve quality of referrals to specialist services
        ii. Focus on implementing best practice within social care, domiciliary care, care homes and specialist services
    2. Implementing care pathways, particularly post diagnostic support
        i. Support and co-ordination for PLWD and their carers
    3. Supporting carers to care for family members with dementia
        i. Providing support, training and help to navigate/co-ordinate services to families, build resilience and maintain balance across all aspects of their life
    4. Improving end of life care so that PLWD die in a place of their choosing with dignity
        i. Co-ordination amongst different care providers to ensure they understand the end-of-life plan

Early diagnosis – in the community

- **NICE guidelines suggest assessment and diagnosis take place in non-specialist settings**. This backs up **international models** where **diagnosis is made in Primary Care where possible.**
- GPs, AHPs and nurses can decrease pressure on specialist services through;
  - Assessment and diagnosis in primary care
  - Improving quality of referrals into specialist care
- GPs and colleagues within primary care are also often the first contact for someone living with dementia, but many studies across UK and internationally show a lack of confidence from GPs, AHPs and nurses within primary care to diagnose dementia
- Increased training, awareness and new dementia models within primary care can all help towards optimising resource capacity and achieving earlier diagnosis of dementia
- Some diagnosis models suggest a 3-tier approach 1) initial assessment in primary care 2) a second assessment/diagnosis by dementia care experts within primary care 3) referral to memory clinics for dementia diagnosis.



Improving Primary Care Assessment/ Diagnosis

- Training for GPs, AHPs and nurses aligned with the 'Good work' framework and international best practice
- Funding/frameworks in place to encourage GPs and AHPs to attend training
- Increase confidence of GPs and AHPs to improve dementia diagnosis/quality of referrals to specialist services
- Support framework for GPs and AHPs including toolkits, guidelines and regular training
- Rapid access to dementia experts in primary care and specialist memory clinics

Early diagnosis

Primary Care Assessment

Primary Care

- Training for GPs, AHPS and nurses based on the 'Good Work Framework' for dementia awareness and to spot early signs of dementia
- Training to undertake some testing to identify people who may have dementia
- Reduce strain on specialist memory clinics by improving quality of referrals
- Remove barriers to GPs and AHPs attending training
- Consider delivering training online to improve accessibility

Primary Care Dementia Experts

Primary Care Dementia Experts

- Identify a cohort of GPs, AHPs and nurses that can act as dementia experts (e.g. GPs, AHPs and nurses with special interest)
- Specialist training for dementia experts based on the 'Good Work Framework'
- People identified in primary care could be referred for additional assessment
- Access to diagnostic tools
- Improve quality of referrals to specialist memory clinics

Specialist Care

Memory Clinics

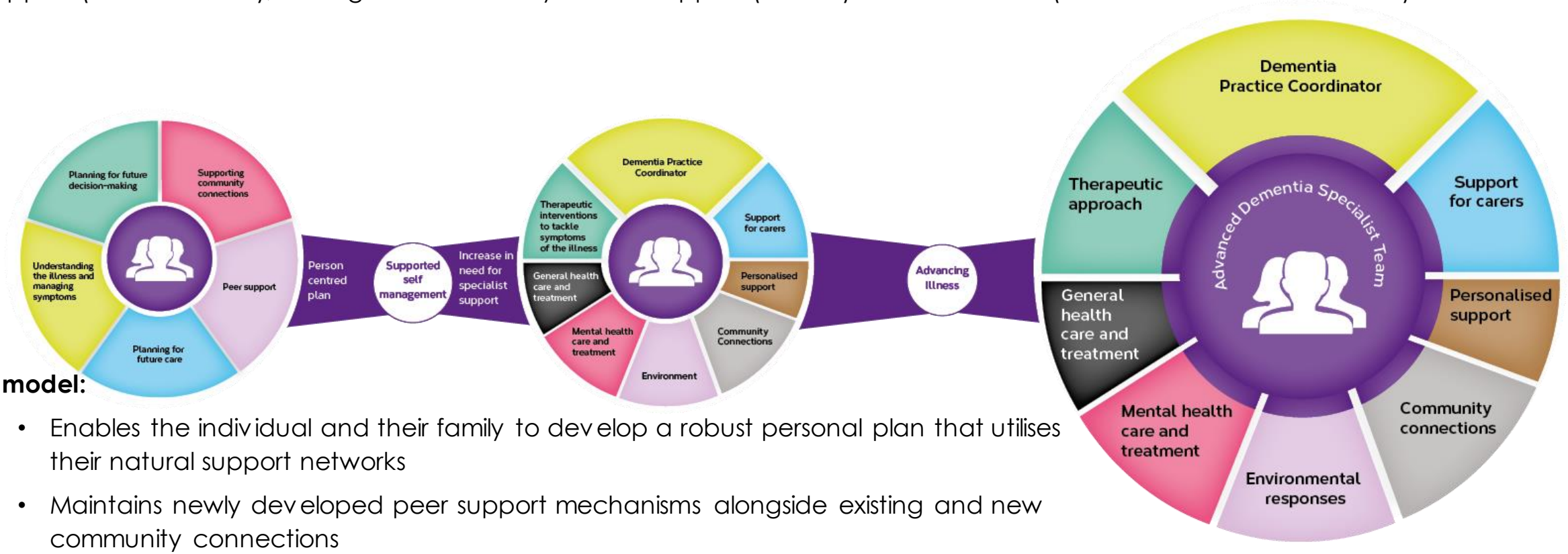
- Services commissioned in line with frameworks
- Memory Services National Accreditation Service MSNAP
- Review of and alignment with best practice from across UK
- Improved brain scan protocols
- Focus on reducing referral to diagnosis times and managing capacity and demand
- Focus on diagnosis rates
- Seamless link into post-diagnostic support

Implementing care pathways

The Wales Dementia Action Plan outlines the need to develop more formal pathways of care for PLWD and this aligns with best practice strategy internationally.

The post-diagnostic support model in Scotland is the only documented model currently being used across the world.

The Scottish model outlines how best PLWD would be supported as their condition progresses. Beginning at Post Diagnostic Support (5 Pillars Model), through to Community-based Support (8 Pillars) and End of Life (Advanced Dementia Model).



The model:

- Enables the individual and their family to develop a robust personal plan that utilises their natural support networks
- Maintains newly developed peer support mechanisms alongside existing and new community connections
- Supports people to live well and independently with dementia for as long as possible

Support and care co-ordination

- Family and carers play a pivotal role in enabling PLWD to live independently in communities for as long as possible
- They will pick up the majority of care, especially in the early stages if an early diagnosis has been made – both national and international strategy is focusing on the need to minimise the impact of caring for someone with dementia
- They need support to build up resilience, develop the skills for caring for someone living with dementia and still be able to maintain a quality of life outside of their care for the PLWD
- Access to flexible respite care is crucial so that families and carers are able to maintain quality of life
- Being involved and supporting their family member with dementia to make decisions about their care is crucial and understanding the services available is key to helping achieve this
- Dementia hubs are playing an increasingly important role in many areas, providing a single point of access and support across a range of services for both PLWD and their carers

Services provided in dementia hubs include:

- Support staff, including dementia support workers, admiral nurses etc.
- Support groups for PLWD and their carers
- Access to local dementia services
- Training programmes for carers

- Activities for PLWD
- Dementia cafés
- Memory Clinics
- Access to finance/ legal/ benefits advice
- Involvement in research opportunities

End of life care

- In the case of dementia, it can be difficult to predict when a person is nearing death. They may present with signs that suggest they are very close to death, but in fact can show these signs for many months, or even years
- In addition, a PLWD may die from another medical condition, for example cancer or heart disease. They may also have infections and minor illnesses on top of these ongoing conditions
- Other conditions and illnesses may mean the person is cared for, or ultimately dies, in a hospital or a facility that does not specialise in dementia care
- Despite knowledge about end-of-life care increasing greatly over the past ten years, particularly in areas such as cancer care, many PLWD still do not receive good quality end-of-life care
- Where possible, advance care planning should take place so that PLWD can make decisions about their care - early diagnosis of dementia plays a key role as a person can make decisions about their end-of-life care alongside family/carers
- It is important that advance care planning is fully embedded in wider inclusive, personalised care and wellbeing planning for dementia and that support is available for Carers when a PLWD passes away
- A coordinated approach between all organisations that care for a PLWD is required – so everyone understands the person's wishes and how they want to be cared for at the end of their life

5. Feedback from structured interviews

Stakeholder Engagement

The development of this strategy has taken place from February 2021 through to January 2022. It has been led by Attain (an independent provider of health support services) who were commissioned by Carmarthenshire County Council on behalf of the WWCP to work with partners, PLWD and their carers to develop a dementia strategy, vision and Dementia Wellbeing Pathway across the region of Carmarthenshire, Ceredigion and Pembrokeshire. The work has been well supported by stakeholders, PLWD and their carers from across the region who have worked very hard to provide local knowledge and insight, through structured stakeholder discussions. The themes stemming from the interviews have been summarised on the following pages.

Many thanks to those who have engaged in this work:

Name
Carmarthenshire County Council adult social care service managers
Carmarthenshire County Council CRT teams
Ceredigion County Council Directors of adult social care
Ceredigion County Council Corporate Managers for Mental Health and Wellbeing and Planned Care
Age Cymru Dyfed
Pembrokeshire County Council Practitioners Forum
Pembrokeshire Association of Voluntary Services
Pembrokeshire Association of Voluntary Services Provider Forum
Hywel Dda University Health Board (HDUHB) Long term Conditions Team
HDUHB regional admiral nurse team
HDUHB Occupational Therapy Mental Health Team – Older Adults
HDUHB Acute Hospitals Dementia Wellbeing Team
HDUHB Older Adults Mental Health Team
HDUHB Heads of service - Therapies
HDUHB Dementia Wellbeing Community Team
Regional Care Home Provider Forum
Healthier Pembrokeshire Forum
Tywi Taf Cluster
Amman Gwendraeth Cluster
North Ceredigion Cluster
South Ceredigion Cluster
North Pembrokeshire Cluster
South Pembrokeshire

Enormous thanks goes to the 16 carers who gave up their time to provide information on the experiences of the people they are caring for as well as from their own caring perspective – this strategy would not be possible without your input.

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The themes stemming from the interviews with carers have influenced the development of the service model pathway and the recommendations within this report.

Wellbeing, risk reduction and delaying onset, raising awareness and understanding		Recognition, identification and initial support		Assessment and diagnosis
Training - Mainly have to work it out oneself especially after hospital discharge with a catheter. That was an absolute nightmare	Carers need training on how to deal with and cope with the person. I am learning as I go along	I had to work out what to do. Our finance's, business, everything it was overwhelming	No information advice or support. It is only recently that people are beginning to help me	Couldn't get anyone to admit to the diagnosis
Absolutely no training - had to find out by myself. Got lots of leaflets but I really needed someone to sit with me and explain things	Rather a lot of confused phone calls from carers' association. No help from the GP or the carers' association	Stumbled along in the dark. Given support through a fluke re enquiring about council tax	Information and advice at the very beginning was great but there was no joined up thinking	Went to the GP and gave diagnosis of dementia - wanted a referral to MH services in case it was a dementia that could be treated - took 2 years
Took ages to connect with the incontinence nurse. Now trying to get through to the dentist	No information - I was reluctant to get help, I thought I could cope. But it was so distressing	Have so much paperwork I loose track of what is what. Half the time I don't know what to do and I don't want to keep going on	Carers and PLWD need clear and accessible information connecting them to local peer groups for support at the outset	Never got to the bottom re diagnosis. Don't understand what type of dementia he has. I would like to know what type of dementia he has
Our local library used to have a day centre. It would be useful to have a day centre to go to (Aberystwyth)	Llanethlli information and training over 4 weeks was very helpful - addresses numbers, websites, of services	What provision is there to protect people with dementia who live on their own? Should be high for identification of frailty in GP surgeries	Best people who have helped - Alzheimer's society, I get a call every month and advice on how to claim attendance allowance	No joined up thinking from the psychiatric dept. Just handed us over to the GP who did nothing

The themes stemming from the interviews with carers have influenced the development of the service model pathway and the recommendations within this report.

wwcp Partneriaeth Gofal Gorllewin Cymru West Wales Care Partnership

Attain

Assessment and diagnosis	Living well with dementia		The need for increased support	
We saw so many people in the first 12 months. First contact was crossroads and was sign posted to a lot of different activities e.g. dementia cafes	It would be good to have a person help sort out my problems rather than me trying to sort things out and find my way	COVID - Made things 10 time worse as you can't meet anyone. Day service in Cardigan has closed and would have been good to take her	Used to do zoom - music - oblivious to it all. Didn't work for my husband and other carers have said that zoom really doesn't work for those with dementia	Admiral nurse came out and went with the carers to see mum to help support them with their caring role - if mum refuses will leave it up to the family
Diagnosed in 2019. Saw the consultant twice, was given a prescription and not seen anyone since	Doesn't appear to be any activities - quite rural where we live and have to travel half an hour to get anywhere (Ceredigion)	To have a day centre specifically for people with dementia or people present to support people with dementia would be good	Consultants in hospitals need to be trained in power of attorney for health. Hospital staff need training - They lost his glasses, hearing aids and his bottom teeth	Everyone has been wonderful after dad fell - social worker, she acted straight away she liaised with the hospital and got him a place in a nursing home
I was inundated with leaflets and phone calls but I had no idea as to who they were, it was a step into a very deep pool	So many services are providing support but are not talking to each other so I have to tell them what has happened	Made it through lock down with no respite and reduced respite now. Please reinstate all day-care facilities. Carers and those with dementia need it	I live out of the area and find it difficult to know what services there are in my mum's area. GP surgery try to keep in contact	The guilt and stress when he had to go into a home, failure, marriage vows come into question - splitting myself in half - relief and guilt
2019 GP had tried to do a dementia test but my husband couldn't hear. I asked to be referred to hospital. 1yr later was referred	I feel now that he has his diagnosis, I can call on people but there is nowhere to go. Could be sat in 5 days a week - there is nothing (Carms)	More than one carer asked for activities targeted at younger people. List of activities sent out to carers each week is phenomenal - lots of things to do (Pembs)	Direct payment: Great as you can have the money but no good if you can't get the care in place	Very disappointed in the care - it was a dementia specialist ward no specific treatment didn't even check if he was eating or drinking

The themes stemming from the interviews with frontline staff have influenced the development of the service model pathway and the recommendations within this report.

Wellbeing, risk reduction and delaying onset, raising awareness and understanding		Recognition, identification and initial support		Assessment and diagnosis
We need a clear understanding of what happens when people get information e.g. who can they turn to for support?	Signposting by GP receptionists can help people access 3rd sector services	People are hitting crisis but don't have a diagnosis – difficult to get CHC without a diagnosis	Support should be provided regardless of diagnosis, including CHC, as it is based on need	Training for all - basic understanding to managing complex behaviours - enabling people to recognise signs, what to expect to support PLWD
We need to maximise the use of DEWIS across the region by professionals and the public	Delaying things results in emergency admissions and those being admitted have more chronic conditions	Community activities need developing and co-ordinating – Pembrokeshire is more mature	There are lots of organisations and communities and it can be a barrier for PLWD/carers to access	We need a standardised approach to diagnosis regardless of where it takes place
Accessing GP, dentist, hearing clinics has become more difficult since COVID - people jumping through hoops and increases stress for the carer	Support care home staff through providing honest information on discharge so they can meet all the person needs. Support staff through training	MDT based in primary care could be making straight forward diagnosis. MAS should be focusing on specialist diagnosis	Carers and PLWD need clear and accessible information connecting them to local peer groups for support at the outset	We need a clear assessment/diagnosis pathway that sits outside mental health services
All staff including dom care and care homes need to be trained to recognise the signs of dementia, especially for those who are deaf, blind and Welsh speakers	We need to raise awareness of young onset dementia and clear pathway and service offer is needed	Access to local networks is better in some areas than others. There is no regional strategic approach to supporting carers	How do people get support without a diagnosis? Dementia is considered separately but shouldn't be, it's very much part of frailty	There needs to be consistency in how people access GP appointments - PLWD many not be able to get past the receptionist or triage

The themes stemming from the interviews with front line staff have influenced the development of the service model pathway and the recommendations within this report.

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Assessment and diagnosis	Living well with dementia		The need for increased support	
Need formal process for secondary care consultant diagnosis and read code included into discharge – how care homes and GPs are made aware	Proactive care planning through HOLISTIC MDT - consistent approach across the region, providing support wellbeing plan around the person	Maximise the use of technology, for professionals, PLWD and their carers e.g. connect carers to support via an APP on the hospital bed Ipads	Education - Training and advice from the Dementia Wellbeing Team (DWT), consider widening membership to include social care and 3rd sector	Care plan and emergency care plan in place for the carer
Is it possible to develop: cognitive assessment for Welsh speakers, people who are blind and a fast track assessment for dementia?	Virtual day services may require a carer present to facilitate. PLWD benefit from being in groups without the carer	Optimise patients wellbeing whilst in hospital through admissions check list - diagnosed, working diagnosis etc. - better use of the acute based DWT	We need to be clear that any new way of working will need to be fully resourced	Training in behavioural interventions is needed for carers and dom care providers – preventing unnecessary residential placements
As the condition progresses the cross over to health services is often difficult and needs to be better. People are hitting crisis but not getting diagnosed	Can social care and 3rd sector become part of the regional dementia wellbeing team?	There needs to be a consistent approach to medication monitoring, review and prescribing in primary care across the region	Community transport colleagues can help MDTs by providing relevant information in relation to the patient	Dementia recognition tool can help the development of behavioural management plans, key behaviours and what interventions can be used
Belief that it can only take place in MAS setting. There is a need for MDT approach to diagnose and prescribe in the community e.g. GPs /AHPs who are fully trained	The overarching thing not addressed is base line wrap around the person, a co-ordinator throughout their journey	Many things are on offer for carers but the ICF carers funding stream is not joined up with the dementia ICF funding stream so there is duplication of effort	Need to ensure employers assess for and implement reasonable adjustments to enable the PLWD services to work	Lots of organisations are going to people's homes and are not talking to each other so people have to keep repeating themselves

Further themes stemming from initial conversations with stakeholders can be found in appendix 2

6. West Wales Dementia Service Vision and Wellbeing Pathway

The following pages contain the dementia service vision and Wellbeing Pathway which builds on the Attain best practice research report circulated in January 2021. This service model pathway has endeavoured to incorporate existing services in West Wales. The service vision and Wellbeing Pathway has been co-designed through engagement with staff from across the region, PLWD and their carers.

The All Wales Dementia Action Plan 2018-2022: As a signatory to the Glasgow Declaration (1) the Welsh Government has previously committed to promote the rights, dignity and autonomy of people living with dementia. Through their engagement with stakeholders they heard about the positive work of Dementia Action Alliance in developing a series of statements with people living with dementia and their carers (2). We have aligned these statements to our Dementia Wellbeing Pathway.

1) https://link.edgepilot.com/s/67f68721/ecxOvtDsBECT3n7RjJzvhg?u=https://www.alzheimer-europe.org/Policy/Glasgow-Declaration-2014
2) https://link.edgepilot.com/s/8d37d66b/NmKURNiXoUaKCjtzSUiWhQ?u=https://www.dementiaaction.org.uk/nationaldementiadeclaration

DRAFT - West Wales vision for dementia services

'Support each person to live well and independently with dementia for as long as possible'

Specialist dementia care support – in the community and in hospital

Intermediate care to support people at the time of increasing need. We maximise comfort and wellbeing – supporting people in their home if possible

Proactive Care and Care Planning as a multi-disciplinary team. Care is co-ordinated ensuring the right help, at the right time

Prevention, Planning and Education within our communities

Communities prepared to support and help

Key enablers to delivery:

- Clear **regional dementia vision, strategy** and **service model** in line with best practice
- Develop **effective** professional and clinical leadership and **governance** to ensure the service model and **new roles** are designed in line with best practice and **are part of the whole health and social care system**
- Strategic and collaborative **PLWD/carer centred commissioning arrangements**
- Cross-organisational working
- **Collective financial** and **performance management**

- **Joint commissioning** for **integrated care,** ensuring **equity** of **access** and **provision across West Wales**
- **Optimise the use of estate** - build on localities and **provide support closer to home** e.g. local meeting places/hubs where people can connect
- **Adapting IT** so that it reflects activity and **captures person centred outcomes.**
- **Shared system transformation** programmes and plans
- **Systematic involvement** of **PLWD** and **their carers** and community in the **design** and **development of the new service model**

- New ways of working expanding the capacity of the Good Work training framework and **new workforce roles** e.g. **Dementia wellbeing connector role**
- **Using technology** to **empower PLWD** and their **carers** and our **staff.**
- **Commissioning** and provision of **primary care services at scale**
- **Interpret population health/social care data, PLWD/family feedback**, design services for networks and **draw in support from wider services**

What good looks like for West Wales – The Dementia Wellbeing Pathway

Working with **partners across West Wales** we have developed **our Dementia Wellbeing Pathway together** focusing on **streamlining pathways** and **placing the PLWD** and **their carers at the centre** of our **service provision.** We will **implement strategies** to **increase early diagnosis, supporting GPs** and **allied health professionals** in **primary care** with **specialist input where needed** as part of an **MDT approach** to **community assessment and diagnosis** and to **improve** the **quality** of **referrals** to **specialist services.**

We will focus on implementing best practice within primary care, social care, care homes, domiciliary care and specialist services. Implementation of **the Dementia Wellbeing Pathway** will include the development of the diagnostic pathway and post diagnostic support, **support and co-ordination for PLWD and their carers** and supporting carers to care for family members living with dementia. We will provide **support, training and help to navigate/co-ordinate services to families**, **build resilience** and **maintain balance across all aspects of their life**. We will **improve end of life care** so that **PLWD die in a place of their choosing** with **dignity** and **improve co-ordination across different care providers to ensure they understand the end-of-life care plan.**

Dementia action plan Wales 2018-22

As a signatory to the Glasgow Declaration (1) the Welsh Government has previously committed to promote the rights, dignity and autonomy of people living with dementia. Through the Government's engagement with stakeholders they heard about the positive work of Dementia Action Alliance in developing a series of statements with people living with dementia and their carers (2)

Dementia Statements reflect the things that people with dementia and carers say are essential to their quality of life. These statements were developed by people with dementia and their carers, and the person with dementia is at the centre of these statements. The "we" used in these statements encompasses people with any type of dementia regardless of age, stage or severity; their carers; families; and everyone else affected by dementia.

These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law and are a rallying call to improve the lives of people with dementia. These Statements recognise that people with dementia shouldn't be treated differently because of their diagnosis.

We have aligned the dementia statements to the new West Wales Dementia Wellbeing Pathway and the recommendations within this strategy have also been aligned.

For more information see:

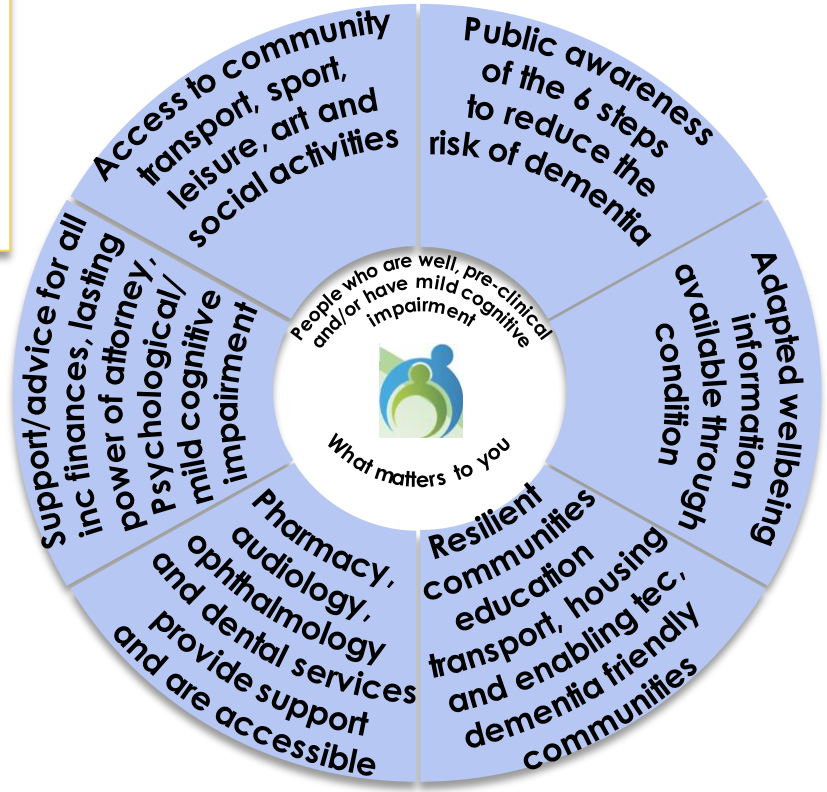
1. https://link.edgepilot.com/s/67f68721/ecxOvtDsBECT3n7RjIzvhg?u=https://www.alzheimer-europe.org/Policy/Glasgow-Declaration-2014
2. https://link.edgepilot.com/s/8d37d66b/NmKURNiXoUaKCjtzSUiWhQ?u=https://www.dementiaaction.org.uk/nationaldementiadeclaration

What good looks like for West Wales – The draft dementia wellbeing pathway

Wellbeing, risk reduction, delaying onset, raising awareness and understanding

Creating dementia friendly communities, making dementia everybody's business

We have the right to continue with day-to-day and familylife, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.



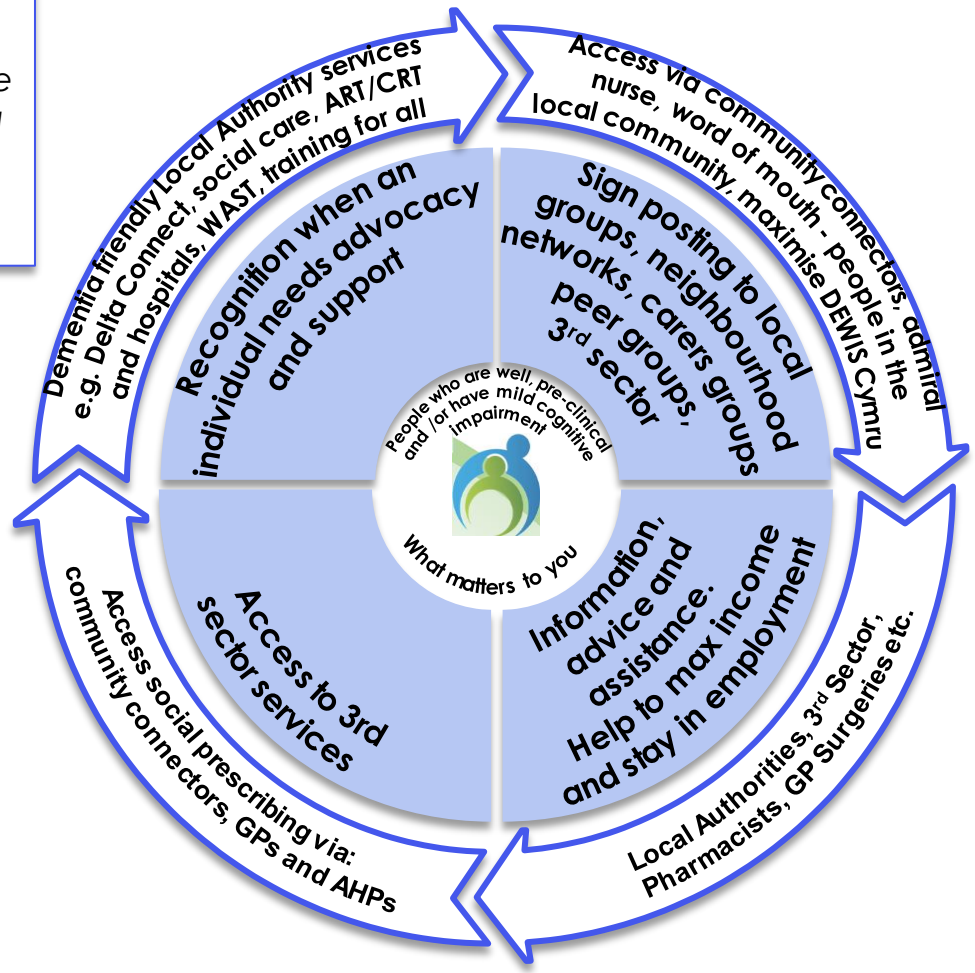
Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks

What good looks like for West Wales – The draft dementia wellbeing pathway

Recognition, Identification, Support and Training

Each person gets fair access to care regardless of diagnosis

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.



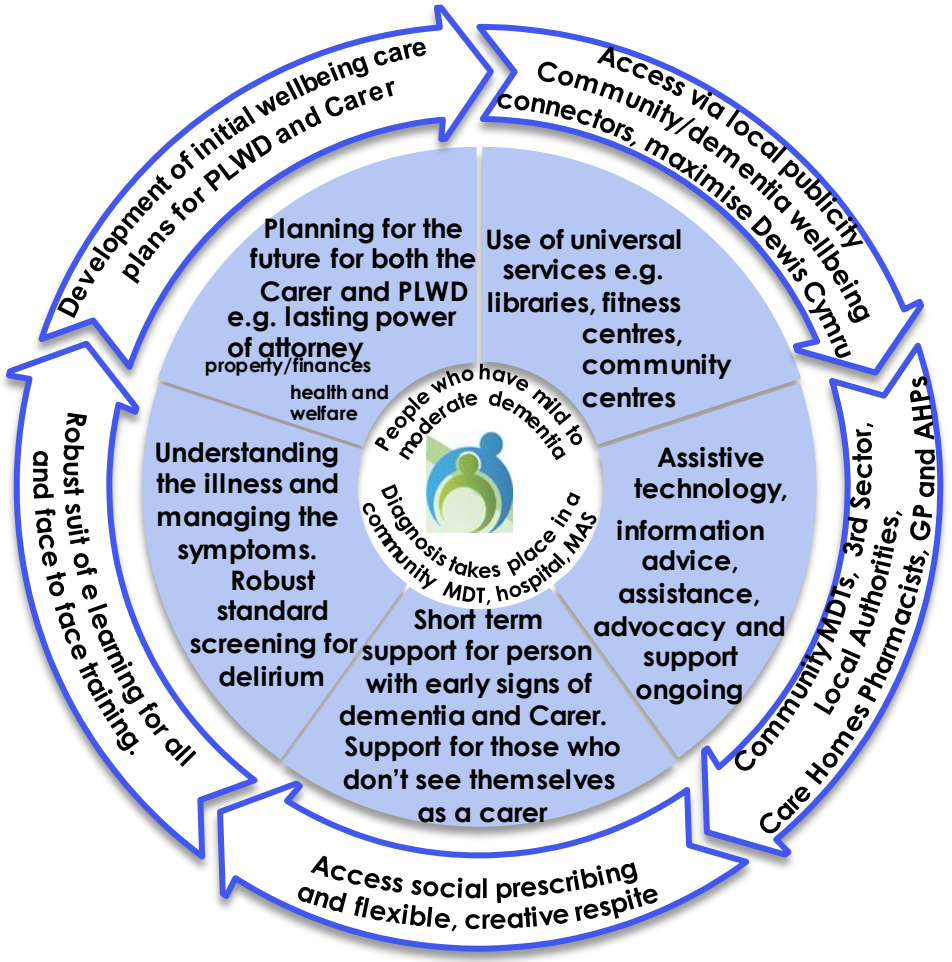
Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks

What good looks like for West Wales – The draft dementia wellbeing pathway

Assessment and diagnosis

Each person is seen as an individual

We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.



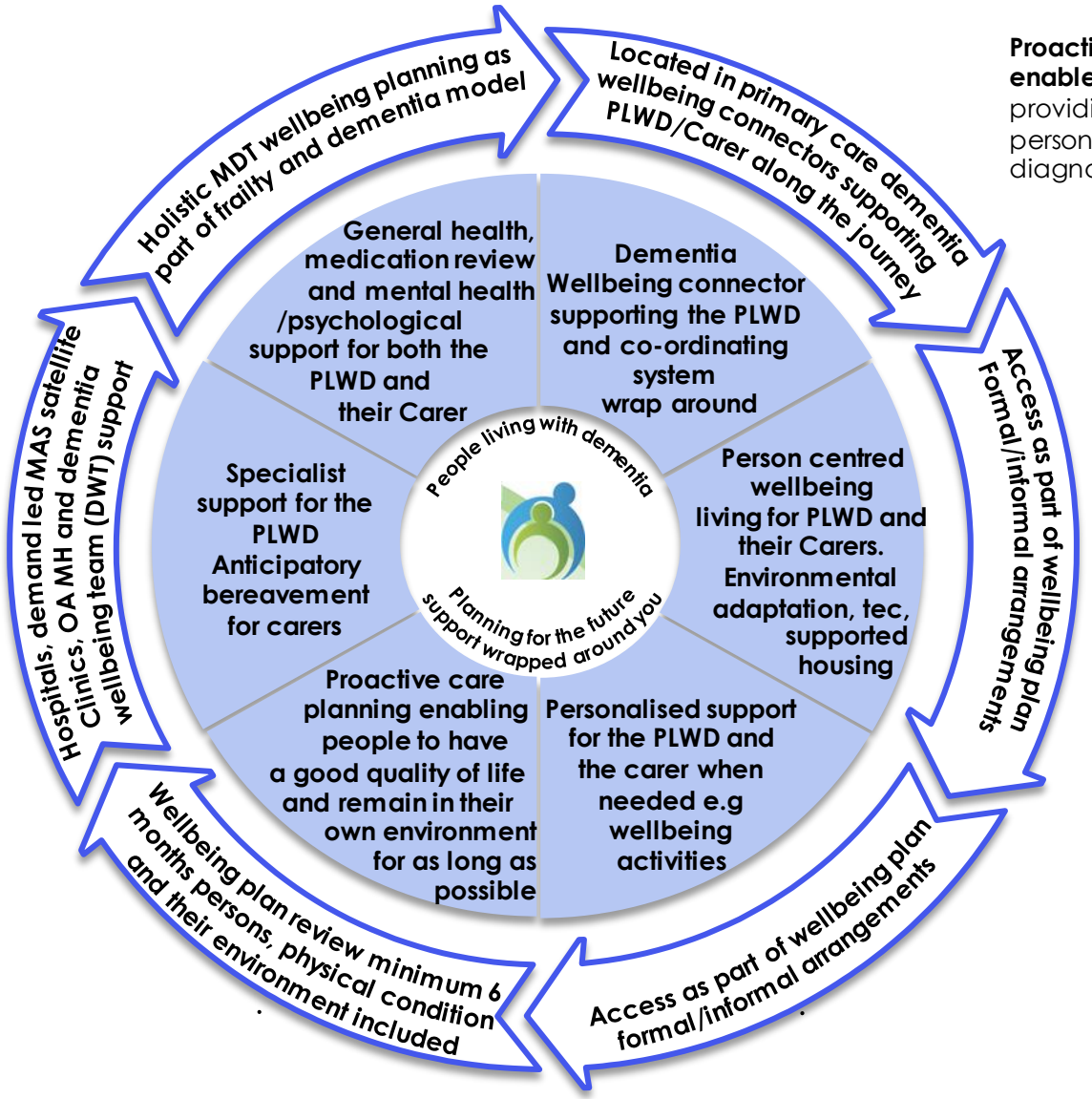
Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks

What good looks like for West Wales – The draft dementia wellbeing pathway

Living well with dementia

Care is co-ordinated

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future. We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.



Proactive care planning through HOLISTIC MDT (colleagues enabled to attend virtually) - consistent regional approach, providing stable support and wellbeing plan around the person and where appropriate, their carer, regardless of diagnosis including:

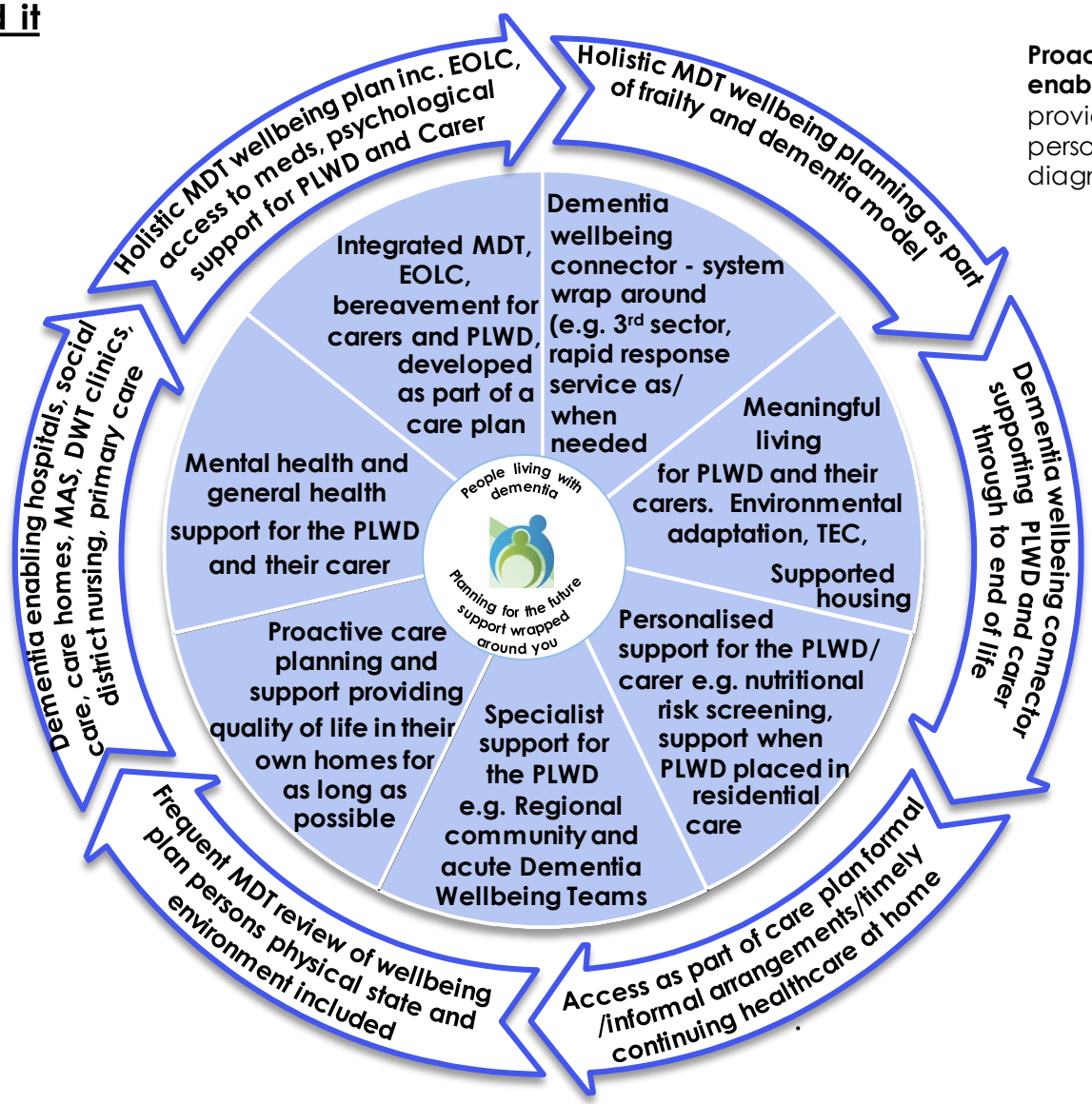
- Dementia wellbeing connector
- GP
- Advocate
- Social care
- District nurse (DN)
- Allied health professionals (AHPs) e.g. OTs, physio, dietetics, speech and language etc.
- Key workers/ assistive technology lead
- Admiral nurse
- Primary care
- 3rd sector
- Pharmacist
- Psychologist
- Care homes
- Older Adult mental health
- Adult MH for young onset
- Advice and advice on training as required from DWTs in the community and acute settings
- Secondary care and SPC consultants as required

Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks

What good looks like for West Wales – The draft dementia wellbeing pathway

Increased support when you need it

All staff are prepared to care
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.



Implementation of the Good Work Framework - we need to consider the **learning and development needs** of **everyone who is affected** in some way **by dementia**. This includes people living with dementia, carers, frontline staff, managers, commissioners, regulators, researchers, shopkeepers, next door neighbours etc. Resulting in **people** who are **informed**, people who are **skilled** and people who can **act as influencers**

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Proactive care planning through HOLISITC MDT (colleagues enabled to attend virtually) - consistent regional approach, providing stable support and wellbeing plan around the person and where appropriate, their carer, regardless od diagnosis including:

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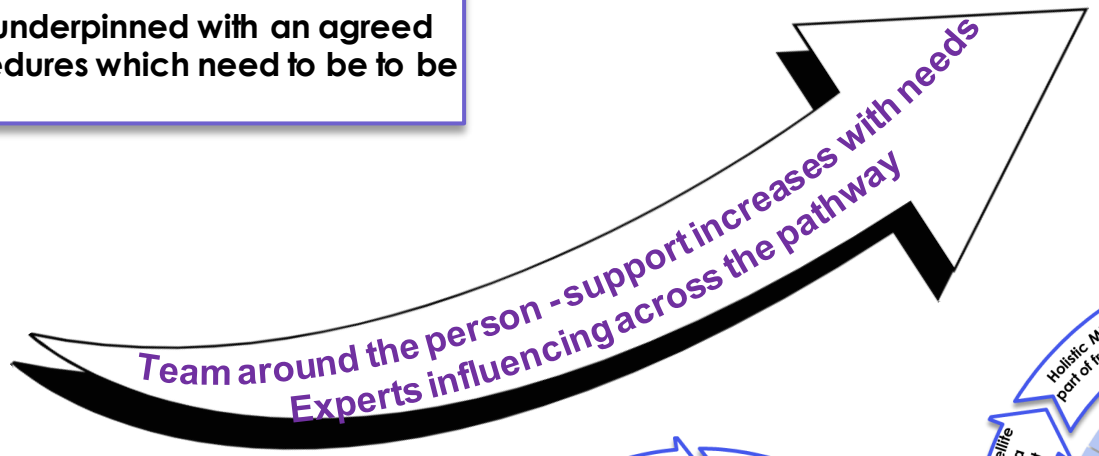
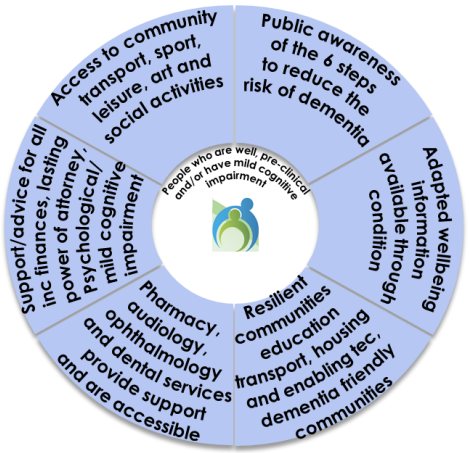
- Secondary care and SPC consultants as required

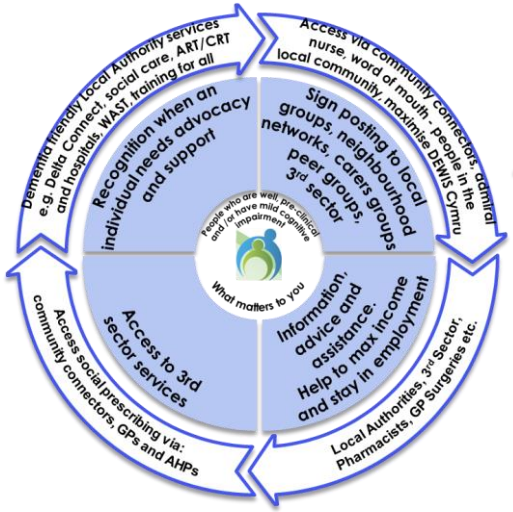
Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks

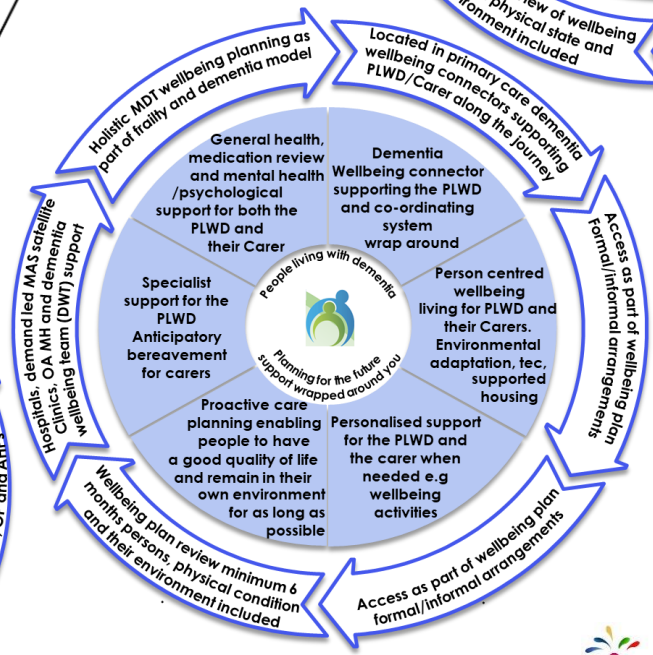
What good looks like for West Wales – The draft dementia wellbeing pathway

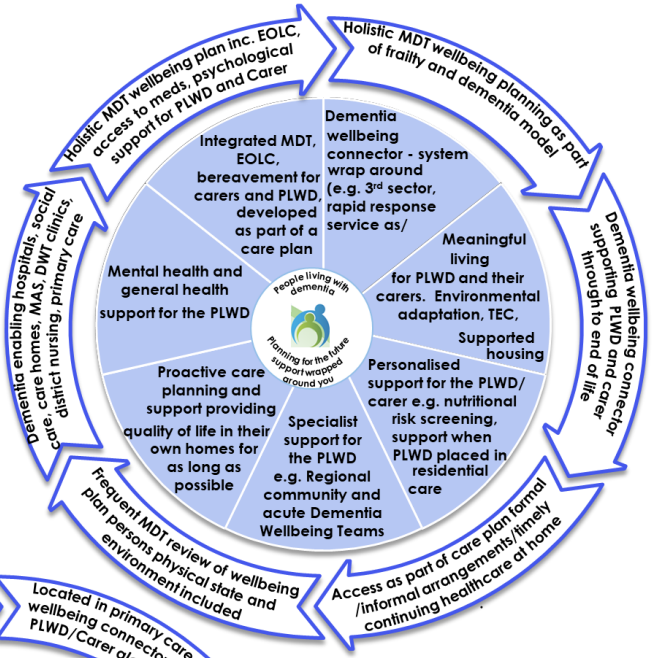
- This pathway places the PLWD and their carer at the centre of service support. It illustrates a new more joined up way of providing services. It is based on best practice and existing services within West Wales.
- The service model should be underpinned with an agreed set of service operating procedures which need to be to be developed











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Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks

Services aligned to the dementia wellbeing pathway

Attain

Wellbeing, risk reduction and delaying onset, raising awareness and understanding

Everyday services:

- Community networks and activities
- Sports and leisure activities
- Health and arts activities
- Libraries
- Cinemas
- Shops
- GP surgeries
- Police
- Fire service
- Dentists
- Opticians
- Audiology
- Pharmacies
- Education
- Housing
- Transport

Recognition, identification support and training

Information, Advice and Assistance - Local Authority's statutory responsibility. Initial advice and information is provided at the initial entry point into social care.

  - Delta - for Carms,
  - Porth Gofal for Ceredigion
  - XXX for Pembs.
- Community networks
- 3rd sector services/activities
- Community/dementia wellbeing connectors/ social prescribers
- Local authority staff e.g. social care support workers, social workers, domiciliary care, Delta Connect,
- GPs and primary care staff
- Allied health professionals
- District nurses
- CRT/ART teams
- Care homes
- Community transport
- Hospital heath staff
- Welsh ambulance service
- Everyday services

Assessment and diagnosis

MDT assessment in the community by trained staff with support from MAS. Hospital based MAS assessment for specialist diagnosis

- Community MDT: Dementia wellbeing connector, GPs, allied health professionals, nurses (all fully trained) see list on wheel 3 MAS – community based
- MAS hospital based
- 3rd sector – initial information and support post diagnosis
- Admiral nurse

Living well with dementia

Community MDT proactively care planning with dementia coordinator

- Person centred wellbeing activities available across the 3 counties to meet the needs of PLWD for both young and old
- Everyday services

Increased support when you need it

Timely access to services including CHC assessment, care packages agreed regardless of dementia diagnosis

- Dementia wellbeing connector
- Admiral nurse
- CRT/ART – health and social care
- Local authority staff e.g. social care support workers, social workers, domiciliary care, Delta Connect
- Care homes
- GPs and primary care staff
- Allied health professionals
- District nursing
- Specialist palliative care services
- Dementia wellbeing service community
- Dementia Wellbeing service hospitals

People with cognitive impairment should be able to be as independent as possible with people supporting them in everyday life. Access to services and support should be regardless of diagnosis. The pathway is designed to enable wrap around care for the PLWD and their carer, with people accessing support as and when they need it.

7. Our approach to Implementing the Dementia Wellbeing Pathway

The following slides summarise the priority areas required in order to implement the new dementia strategy and well being pathway.

Along with the co-design of the Dementia Wellbeing Pathway, the priority areas have been identified following extensive stakeholder engagement across West Wales and take into account best practice as well as the All Wales Dementia Action Plan and the recently published All Wales Dementia Care Pathway Standards.

The All Wales Dementia Action Plan 2018-2022: As a signatory to the Glasgow Declaration (1) the Welsh Government has previously committed to promote the rights, dignity and autonomy of people living with dementia. Through their engagement with stakeholders they heard about the positive work of Dementia Action Alliance in developing a series of statements with people living with dementia and their carers (2). We have aligned these statements to our priorities and recommendations.

1) https://link.edgepilot.com/s/67f68721/ecxOvtDsBECT3n7RjIzvhg?u=https://www.alzheimer-europe.org/Policy/Glasgow-Declaration-2014
2) https://link.edgepilot.com/s/8d37d66b/NmKURNiXoUqKCjtzSUiWhQ?u=https://www.dementiaaction.org.uk/nationaldementiadeclaration

Wellbeing, risk reduction, delaying onset, raising awareness and understanding

Creating dementia friendly communities, making dementia everybody's business

We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

What we are doing and our plans in this area:

Implementation of the Good Work framework – Training for <u>ALL</u>	• **Refresh** the **West Wales learning needs analysis training framework** and work with **partners** to **implement it.** Ensuring that **training provided** is **evidence and rights based approach where appropriate** and to also build in **training provided** by the **Welsh Government** to help **achieve** the **implementation** of the **All Wales Dementia Care Pathway of Standards (AWDCPS)** • **All staff**, including those in everyday services and services such **as domiciliary care and care homes**, to be **trained to recognise** the **signs of dementia** and be trained in **how best to support PLWD** - appropriate to the level of contact - from **basic understanding** to **managing behavioural expression of unmet need** - enabling generic services (e.g. **social work, personal assistants, domiciliary care, care homes, district nursing, OT, physio etc.**) to **support PLWD especially for those who are deaf, blind and Welsh speakers** • **Training for all staff** in basic understanding to **managing person centred care/behavioural expression of unmet need - enabling people to recognise signs, what to expect to support PLWD** • **Arrange** for those **professionals** who are **interested** to be **trained** through the **All Wales faculty dementia diagnosis course** which is **available for all professionals – consider if a bespoke regional training would be appropriate for the West Wales region** • Ensure there is access to **training in behavioural interventions** for **carers and domiciliary care providers** – **preventing unnecessary residential placements** <u>All Wales Dementia Care Pathway of Standards (AWDCPS)</u> • **Within 12 weeks** of **receiving a diagnosis**, **PLWD** will be **offered education** and **information** on the importance of **physical health activities to support** and **promote health**. (AWDCPS 9) • **Implementing the All Wales expert by experience courses (Licenced by Harvard university) - PLWD, 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.** (AWDCPS 10) • **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. (AWDCP 17)
Communication, raising awareness enabling access to timely information/ services	• **Promote** the UK and Welsh Government **public health messages** across the region • **Raise awareness** of **young onset dementia** and **develop a clear service offer** • **Carers** and **people living with dementia** (PLWD) need **clear** and **accessible information connecting** them to **local peer groups** for **support** at the **outset** • **Maximise** the **use of DEWIS** across the region by **professionals** and the **public** • Create a **standard approach across organisations** for **the provision** of **information** to **PLWD** and their **carers** • **Primary care** consider how **PLWD access GP appointments** - PLWD may not be able to get past the receptionist or the triage system if living on their own • The **introduction** of **a Dementia wellbeing connector role**, which will work with **local services** within the **communities** they are **aligned to** and will enable **better access** to **everyday services** such as dentists, opticians and GP surgeries • **Develop** a **range** of **individual** and **group based physical** and **activity based interventions** and **opportunities** that are **person centred** for **PLWD** to access • **Recognise** that **transport,** particularly in **rural areas,** to **get people** to **community activities** is challenging and **identify ways** of addressing this

Recognition, identification support and training

Attain

Each person gets fair access to care

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

What we are doing and our plans in this area

Proactively supporting people	• **Strengthen access** to **local networks across** the **region** for those with **mild cognitive impairment** and for **those** with **dementia** • Ensure **dementia** is an **indicator** as part of **risk stratification within primary care** and PLWD and their carers who require support **receive proactive MDT care planning** with **support from the Dementia wellbeing connector** • **Develop** a **proactive case management approach (shared care/decision making)** through **MDT working, developing plans** to **lower** the **likelihood** of **PLWD hitting crisis,** even for those who don't have a diagnosis All Wales Dementia Care Pathway of Standards (AWDCPS) • **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 interv ention (AWDCPS 8).
Support regardless of diagnosis	• Carers and people suspected of highly likely living with dementia to **access clear** and **accessible information** connecting them to **local peer groups for support at the outset** • Carers and people suspected of highly likely living with dementia receive **advice** and **support** in relation to managing their every day lives throughout their journey • **Community activities** need **developing** and **co-ordinating** for people suspected of highly likely living with dementia and their carers – **activities** should **be person centred** and be **available regardless of diagnosis**
Enabling structures	• Develop a **regional strategic/co-ordinated approach** to **supporting carers** – consider top slicing the dementia ICF funding to be included in the carers' ICF funding, thereby ensuring all carers' services support those who are caring for people living with dementia • **Review CHC assessments** which have taken place over the past 18 months **to identify whether people are accessing CHC regardless of a dementia diagnosis** – develop a report and action plan to address, if needed • Develop a **comprehensive communication programme** to **promote** the **strategy** and its **messages**. Keep the plan alive and ensure the **public** are **aware** of any **new service developments** in their area or across the region. Regularly report progress and review the plan via the WWCP Dementia Steering Group

Assessment and diagnosis

Attain

Each person is seen as an individual

We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

What we are doing and our plans in this area

Getting the diagnosis pathway and information right first time	• **Develop** a **regional diagnosis pathway, maximising** the **use** of **AHPs, designing new ways to diagnose in the community,** develop an **outline business case** to **implement** the **new pathway** with **modelled resourcing**. The **new pathway** will include the **implementation** of the **AWDCPS: 3, 5, 6, 7 and 15** – (See standards below). • Ensure the **new pathway includes** a **formal process for acute hospital consultant diagnosis** and **READ codes included into discharge papers** – so care homes and GPs are made aware • Following the recent development of an outline business case, develop a **full business case** for the **Dementia wellbeing connector role, to include system savings aligned to a phased roll out. WWCP dementia steering group to agree** the **preferred option**. Develop **plan** to **implement** the **new role.** All Wales Dementia Care Pathway of Standards (AWDCPS) • **Memory Assessment Services (MAS)** and **Primary Care (GP)** will **adopt** the **READ Codes**. 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** (AWDCPS 3) • **Health** and **social care** services will **provide** the **correct information** to **assist MAS** when they **undertake assessments** and in **providing diagnosis.** This will also **support** the **person** to **manage any identified daily living difficulties.** (AWDCPS 5) • **MAS, within** a **12 week period** from **point of referral**, will **provide** a **range** of **interventions** (listed in the AWDCPS **6**) to **support diagnosis**. **Consider** what **digital platforms** and other **adaptions** and **approaches** are needed to enable the implementation of this standard. • **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**. (AWDCPS7) • **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**. (AWDCPS 15)
Supporting those with a learning disability	• **Ensure the processes in place enable a person with a learning disability receives a cognitive wellbeing check** All Wales Dementia Care Pathway of Standards (AWDCPS) • **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**. (AWDCPS 4)

Living well with dementia

Care is co-ordinated

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part. We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

What we are doing and our plans in this area

Enabling people to have health reviews and to attend appointments	• Following sign off of the full business case, roll out of the **Dementia wellbeing connector service** which will promote **proactive care planning** through **HOLISTIC MDT** - **consistent approach across** the **region**, providing **stable support wellbeing plan around** the **person – develop a regional holistic care plan template** • **Dementia wellbeing connector** to **co-ordinate support throughout** a **person's journey** • **Develop a pre and post diagnostic service (PPDS) standard operating procedure. This will set out expectations, processes and data recording requirements from the PPDS.** • Develop a **consistent approach** to **medication monitoring**, **review** and **prescribing** in **primary care across** the **region** All Wales Dementia Care Pathway of Standards (AWDCPS) • **PLWD** 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. (AWDCPS 14) • **PLWD, 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. Practical streamlining of operational processes will support the service to avoid duplication and maximise opportunities to exercise prudent principles to service delivery. (AWDCPS 18)
System wide response	• **Support PLWD** to **live well; continue** with implementing the **Journey Through Dementia OT programme** which includes implementing **'dementia-friendly design principles' within peoples own environments** and **any new building or service** • Ensure **employers assess** for and **implement reasonable adjustments** to enable the **PLWD to work** • **Regardless of diagnosis, Dementia wellbeing connector** role to act as the **co-ordinator** for the **PLWD reducing** the **likelihood** of **them or their carer having to repeat their story** or to be accountable for relaying information between services – **capturing the essence of who the person was** - explore using the patient knows best APP • **Review <u>ALL</u> initiatives currently funded** by the **Regional Integrated Fund, evidencing outcomes, align funding** to **implement** strategic **priorities, ensure any new way of working is fully resourced** • Consider whether **social workers** from **each county** and **3rd sector colleagues** could **become part** of the **regional dementia wellbeing community team** • **Review community activities** available **across** the **region** for PLWD and support activities for carers. **Address gaps, including activities** for those with **young onset dementia** • **Maximise** the **use of technology**, for **professionals, PLWD** and their **carer** e.g. connect carers to support via an APP on the hospital bed Ipads • **Implement** the **remaining actions** from the **All Wales Dementia Action plan** • **Identify** an **area** in which to **implement the All Wales Dementia Care pathway Standards** in line with the 2 year programme of work outlined in the standards. (AWDCPS 1) All Wales Dementia Care Pathway of Standards (AWDCPS) • Services at the **points of contact** will **provide reasonable adjustments** to care that is meeting the person's needs and personal preferences.(All Wales Dementia Care Pathway Standard 2) • Person-centred **reasonable adjustments** will **support the person to live well** by **maximising their independence** and **ability to participate in their communities.** (All Wales Dementia Care Pathway Standard 2) • 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**. (AWDCPS 12) • 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** (AWDCPS 13) • Organisations and care settings providing **intensive dementia care** (this includes mental health and learning disabilities inpatient settings) **implement the dementia care mapping tool** to evaluate and learn about **person-centred enabling practice**. Supporting **clinical reasoning** and **decision making**. Mental health DCM services will offer DCM support to acute care, prisons and care homes settings. (AWDCPS 16) • **Working in partnership**, the **region** will **deliver** on the requirements of the **agreed data items** (measurement workbook) for **reporting and assurance**. (AWDCPS 20)

Increased support when you need it

All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

What we are doing and our plans in this area

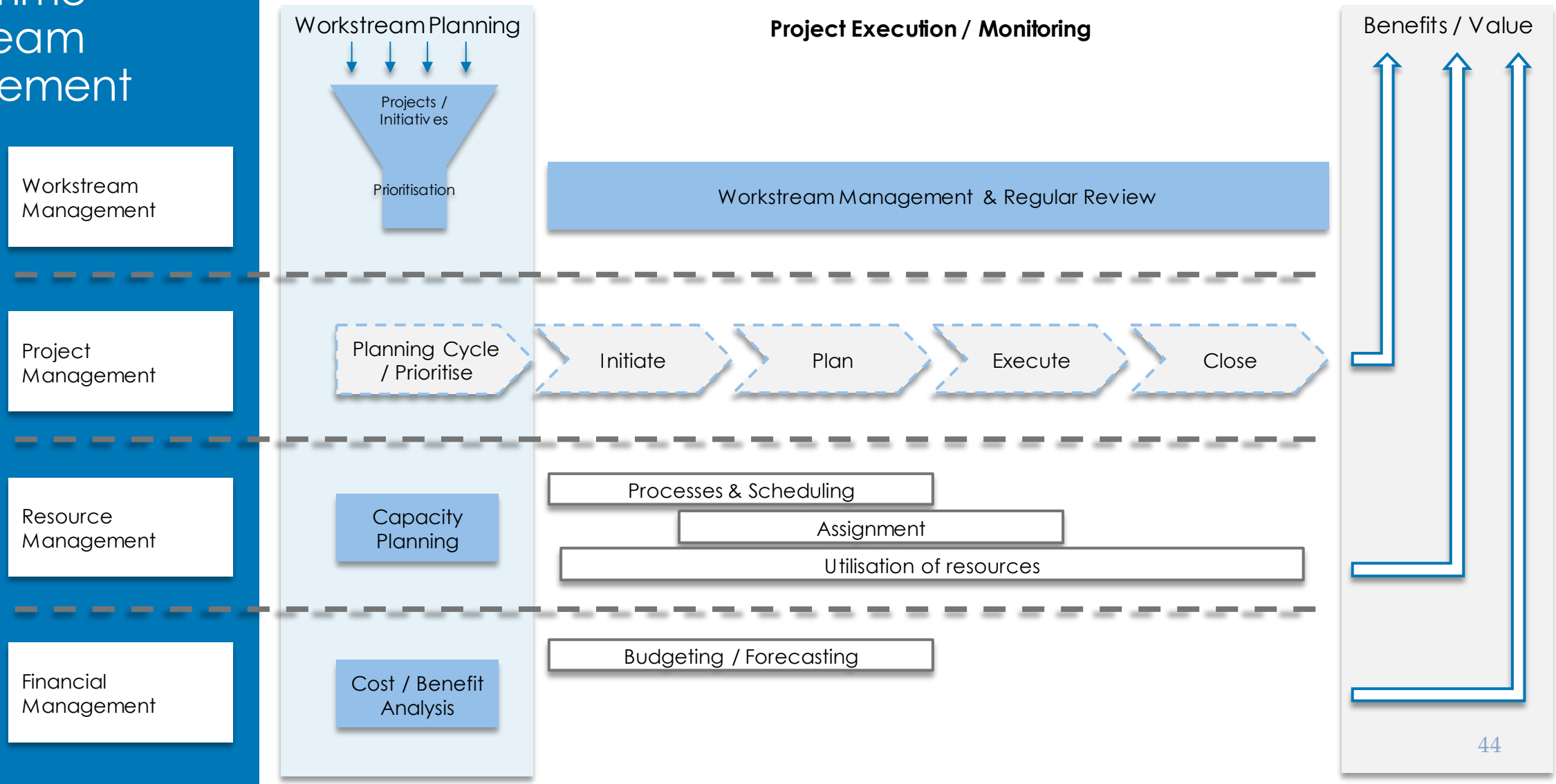
Consistent care while in hospital	• **Optimise patients' wellbeing while in hospital** through **admissions** and **discharge check list** - diagnosed, working diagnosis etc. Fully adopt the **Dementia Friendly Hospital charter**, **raising awareness among staff** and **volunteers, preventing issues** such as **personal effects getting lost** or **hearing aids not being put in correctly** – **develop action plan to implement** and **regularly review** through the **WWCP Dementia Steering group** • Ensure **hospital staff** are **trained** to **understand what power** of **attorney** for **health means** All Wales Dementia Care Pathway of Standards (AWDCPS) • Wales will adopt the **Dementia Friendly Hospital Charter** with a regular review of implementation and outcomes. (AWDCPS 11).
Maximise the power of MDT working, accessing support when you need it	• Develop a **regional, standard, interdisciplinary care plan** and through **proactive MDT working which enables colleagues to join virtually, and shared decision making with the patient and carer, plan ahead** to **prevent crisis** as well as to **increase support as and when it is needed including agreeing ceilings of care - consider** if the **plan** should be placed **in an APP that can be accessed by the patient, carers and colleagues** • **Maximise the circle of support** e.g. **community transport** colleagues can help MDTs by **providing relevant information** in relation to the patient • Ensure that **organisations communicate with each other** rather than PWLD or their carers having to co-ordinate communication across services • Identify **when** the **carer lives outside** the **region** to **ensure** they have **local information** to enable the person they are caring for to access services in their local area • Ensure that there is an **crisis contingency care plan in place for the PLWD and their carer** and that the **carer can also access support when they need it** • **Training in person centred behavioural expressions of unmet need** is needed - **implement the dementia recognition tool across the region** which can help the development of behavioural management plans, key behaviours and identifying what interventions can be used All Wales Dementia Care Pathway of Standards (AWDCPS) • 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**. (AWDCPS 19).

Delivering the initiatives through programme management

In addition to developing the vision, service model pathway, strategy, Attain were asked to review existing regional governance to ensure robust, multi-agency ownership of the ICF Plan, its delivery and evaluation. To begin with Attain highlighted what good programme management looks like (for more detail see appendix 3)
The following slides describe the proposed programme management framework for the Regional Dementia Programme.

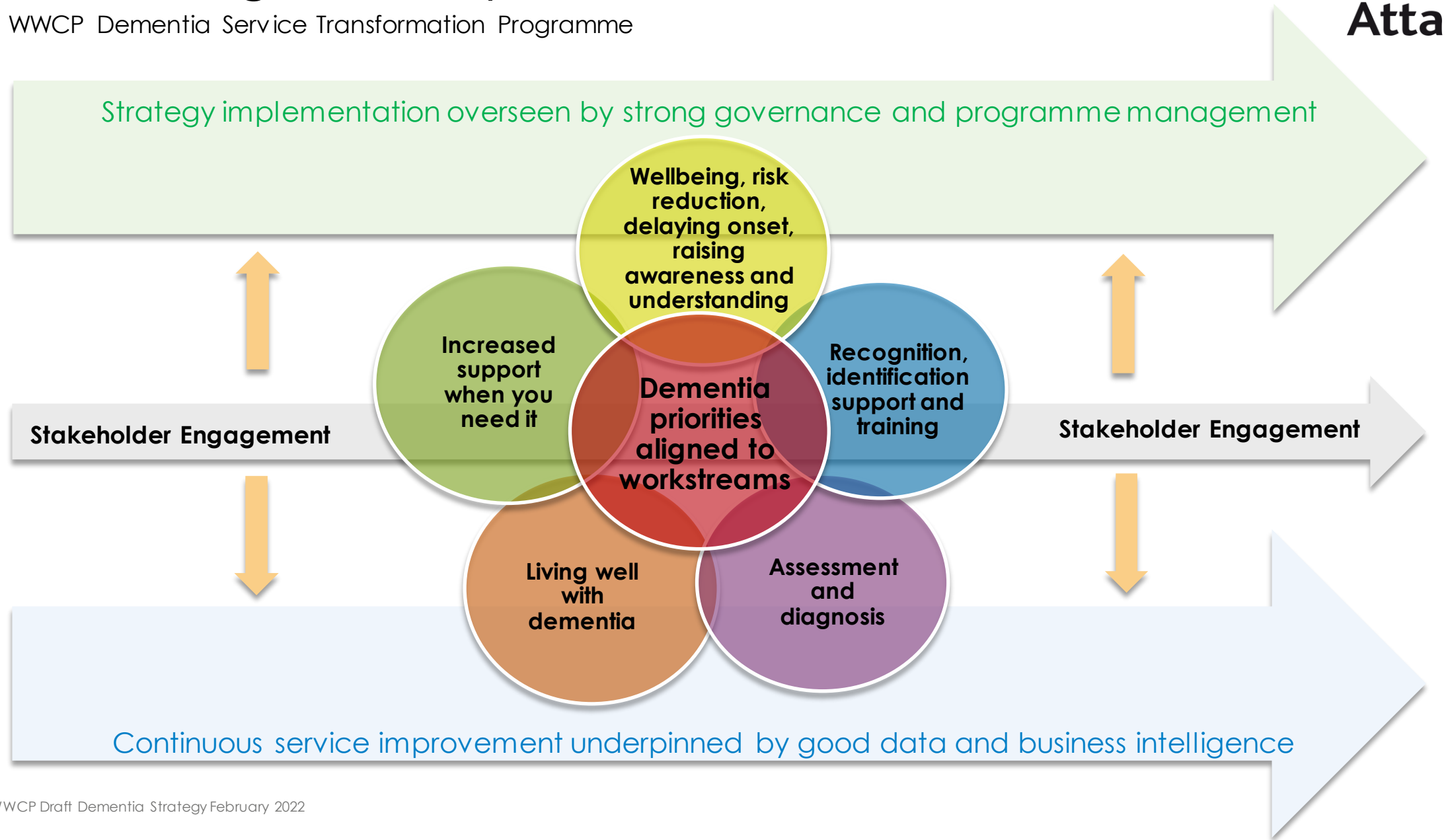
What does good programme management look like?

Proposed Delivery Approach: Programme Workstream Management



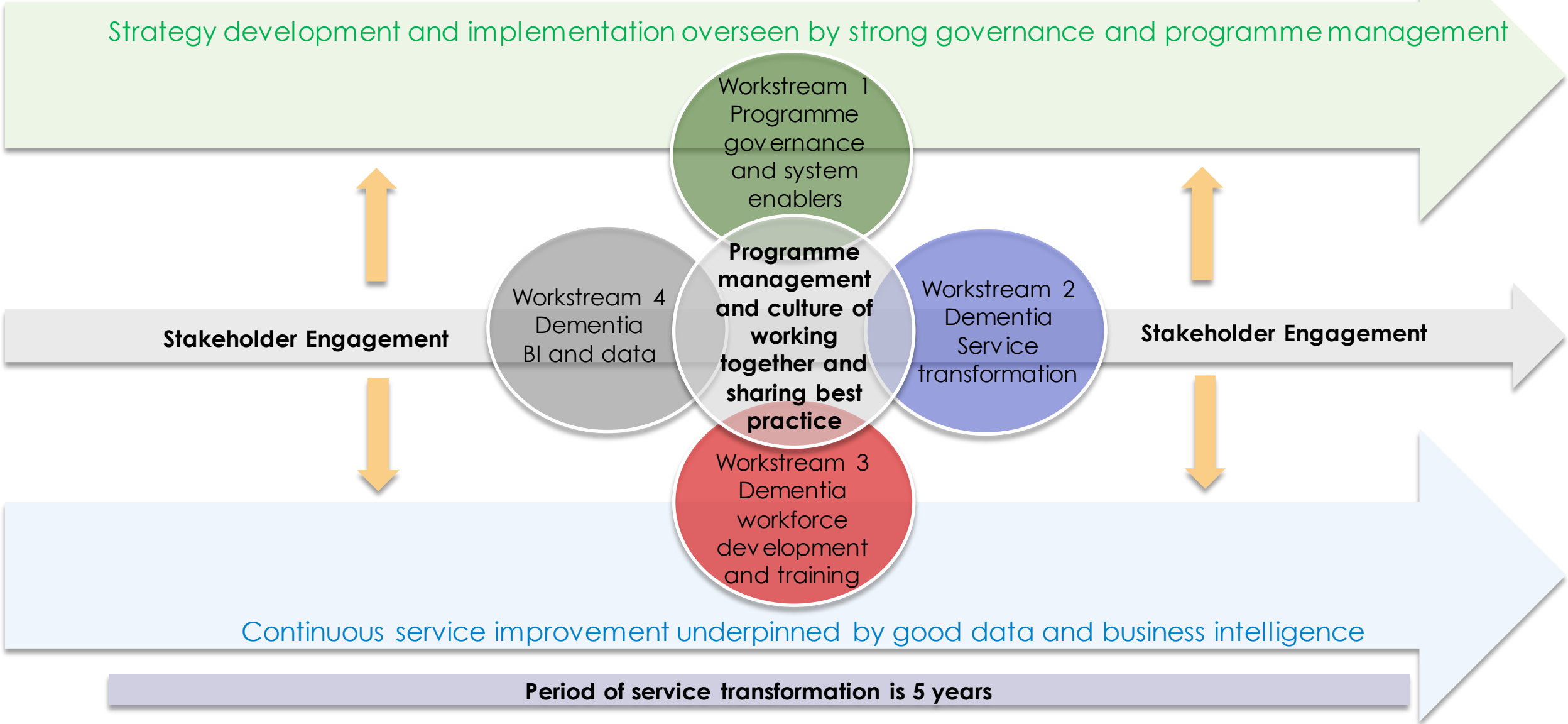
Approach to implementing the Dementia strategy and Wellbeing Pathway

WWCP Dementia Service Transformation Programme



Proposed workstreams to deliver the WWCP Dementia strategy

WWCP Dementia Service Transformation Programme



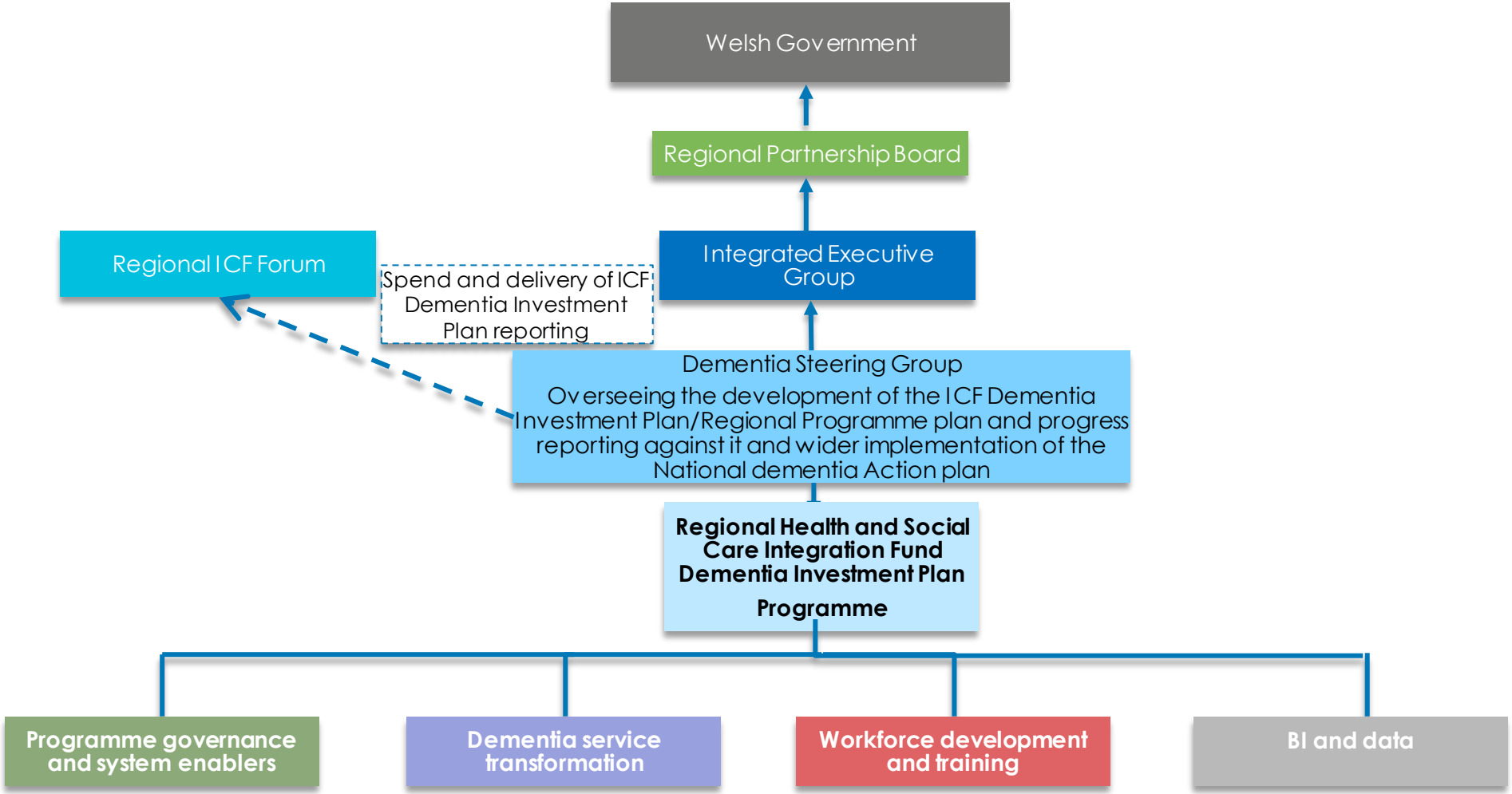
Proposed Delivery Approach: Portfolio Management

The below indicative set of portfolios will provide structure to deliver the next phase of work developing the dementia strategy/programme plan. The dementia strategy priorities are in line with the All Wales dementia care pathway standards and builds on the current good practice already in place. The dementia priorities should be led by a senior leader within the system and will be overseen by an SRO, along with the WWCP dementia steering group. However, the whole programme of work will also be overseen by the Integrated Executive Group and the Regional Partnership Board. Resources will need to be idenfied over the life of the programme to enable continuation of service delivery while frontline staff work to design and develop the services.

	Programme governance and system enablers	Dementia service transformation	Workforce development and training	BI and data
Aim	Implementation of the regional dementia strategy fully singed up to by the WWCP. Robust achievable implementation plans.	Implement recommendations stemming from the dementia strategy that relate to service transformation.	Implement priorities stemming from the dementia strategy that relate to workforce development and training.	Implement priorities stemming from the dementia strategy that relate to a uniform approach to collection of business intelligence and outcomes.
Priority Areas	• Recruit regional programme manager • Regional programme plan developed to deliver the strategy recommendations. • WWCP programme governance structure • Oversight of 2021/22 projects and allocation for 2022 onwards • Enable data intelligence to support decision making and planning • Set up and implement the enabling structures stemming from the recommendations within the strategy • Communication plan running alongside the strategy, raising awareness, promoting service developments locally	• Proactively supporting people • Support regardless of diagnosis • Getting the diagnosis pathway and information right first time • Supporting those with a learning disability • Enabling people to have health reviews and to attend appointments • Actions in relation to implementing a system wide response • Consistent care while in hospital • Maximise the power of MDT working, accessing support when people need it	• Implementation of the Good Work framework – Training for ALL and recommendations in the strategy relating to training e.g. Refresh the West Wales learning needs analysis training framework, work with partners to implement it. Ensuring that all training provided is evidenced based • Development of a workforce plan to support service transformation delivery • Support the development of the dementia recognition tool • Take forward the development and role out of the Dementia wellbeing connector role	• Data driving change – develop ICF dementia programme performance dashboard • Develop the Dementia wellbeing connector full business case with detailed population needs, workforce and demand and capacity modelling for Dementia wellbeing connector role to provide emotional support throughout the assessment period and over the next 48 hours after receiving a diagnosis • Implementation of the dementia strategy recommendations in relation to BI and data.

Patient and Carer co-production - improving patient experience through easy access and standardisation of information, services and user/family voice in service change

Proposed Integrated Care Fund (ICF) Dementia Programme Governance Arrangements



8. Next steps for 2022/23

Next steps

Delivering the programme:

- Agree the rationale to continue funding during 2022/23
- Identify resource to set up and manage the programme of work across partners - recruit to the role
- Create a programme plan, prioritise projects and revise timelines to ensure that there is a realistic and deliverable plan in place. Use Workstream Management as the process for delivery
- Identify Workstream SROs to drive work with PMO support; provide ownership and accountability to deliver
- Regular progress updates should be provided at the monthly WWCP Dementia Steering Group

Implementing the strategy:

- Seek sign off from Integrated Exec Group and Regional Partnership Board, develop communications plan to socialise the strategy so all partners are aware of the direction of travel for dementia services within West Wales.
- Communications plan to cover the life of the strategy, enabling the public to be aware of any new developments in their area
- Update the programme plan with the new service developments required to deliver the dementia wellbeing pathway
- Ensure robust governance is in place to oversee the implementation of the new service initiatives, ensuring all new initiatives take a programme approach reporting progress regularly to the Regional Dementia Steering group

Implementation of the new West Wales Dementia Strategy

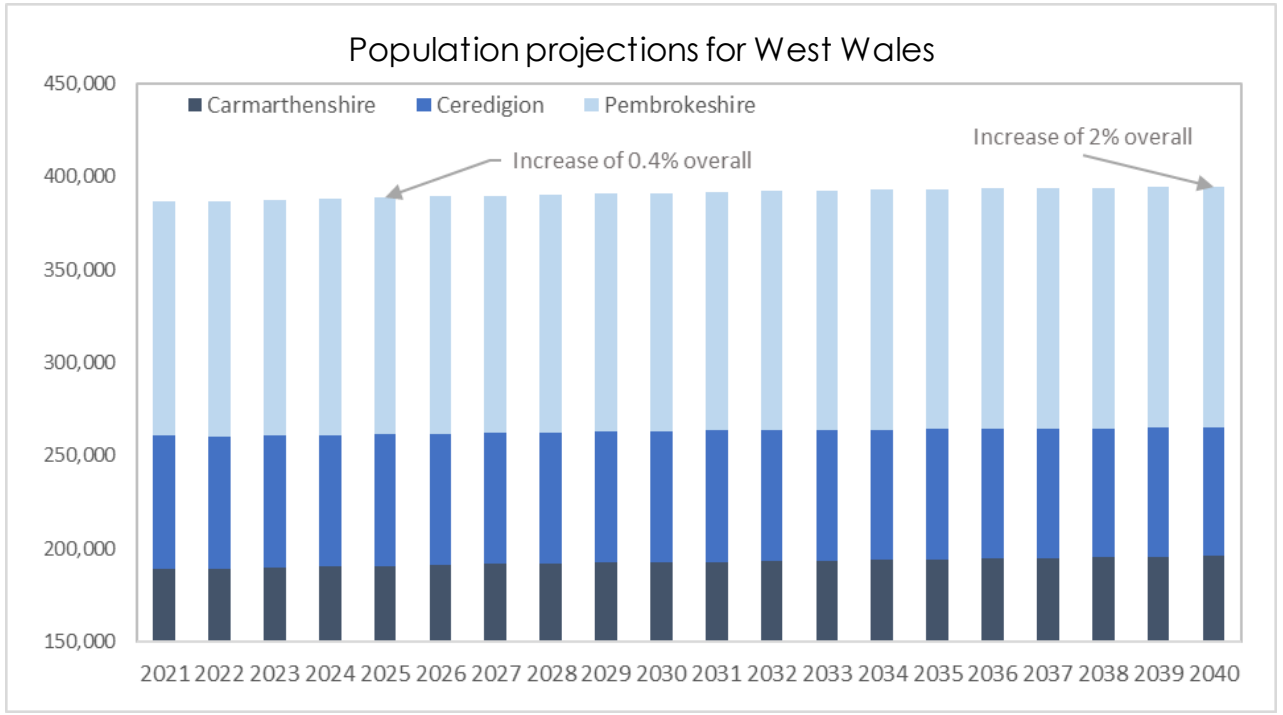
9. Appendix 1: West Wales Population Analysis

West Wales population analysis (ONS)

Overall the population of West Wales looks like it will increase by **0.4% overall by 2025** and by **2% by 2040** (20 years). Pembrokeshire and Carmarthenshire will see the similar population increases of 0.6% and 0.7% by 2025 and 2.7% and 3.5% by 2040. Ceredigion is expected to have a population decrease (0.7% at 2025 and 3% at 2040). However, in terms of age; **all areas are going to see an increase in their elderly populations.**

Overall, the elderly population is set to increase, and the child and working age population decrease

- By 2025 (in 4-5 years) the population of **over 65s is likely to increase by 6%** (over 80s by 11%)
- By 2040 (roughly 20 years from now) the over 65 population is looking likely to increase by 27% and the over 80s 55%
- The over 65s currently make up a quarter of the population. In 5 years around 26.8% and by **2040 it is likely to be nearly a third of the population** with the **over 80s becoming over 10%** (from just over 6% now)



% change from Current

	2025	2030	2035	2040
0-4 yrs	96.6%	93.7%	94.2%	97.4%
5-9 yrs	95.1%	91.1%	88.8%	89.4%
10-14 yrs	99.0%	92.2%	88.4%	86.4%
15-19 yrs	109.5%	111.2%	104.3%	99.9%
20-24 yrs	96.6%	107.2%	109.6%	103.3%
25-29 yrs	89.8%	84.1%	93.4%	96.1%
30-34 yrs	97.1%	87.7%	82.2%	91.3%
35-39 yrs	107.1%	106.4%	97.5%	91.6%
40-44 yrs	102.5%	109.2%	108.5%	100.2%
45-49 yrs	94.3%	99.0%	105.0%	104.5%
50-54 yrs	89.4%	81.2%	85.7%	90.5%
55-59 yrs	95.9%	85.7%	78.6%	83.4%
60-64 yrs	111.3%	108.9%	98.2%	90.8%
65-69 yrs	105.7%	120.5%	118.6%	107.7%
70-74 yrs	92.9%	99.5%	114.0%	112.9%
75-79 yrs	115.9%	108.8%	117.7%	135.7%
80-84 yrs	115.8%	141.4%	134.3%	147.4%
85-89 yrs	105.8%	125.6%	155.4%	150.3%
Age 90+	107.8%	120.1%	145.4%	183.6%

Source: ONS

West Wales Dementia (QOF Register)

The data in this pack is an extract from the GP systems using the QOF definition.

Women make up approximately 62% of the registered dementia patients in West Wales but this is partly due to higher life expectancy in the female population

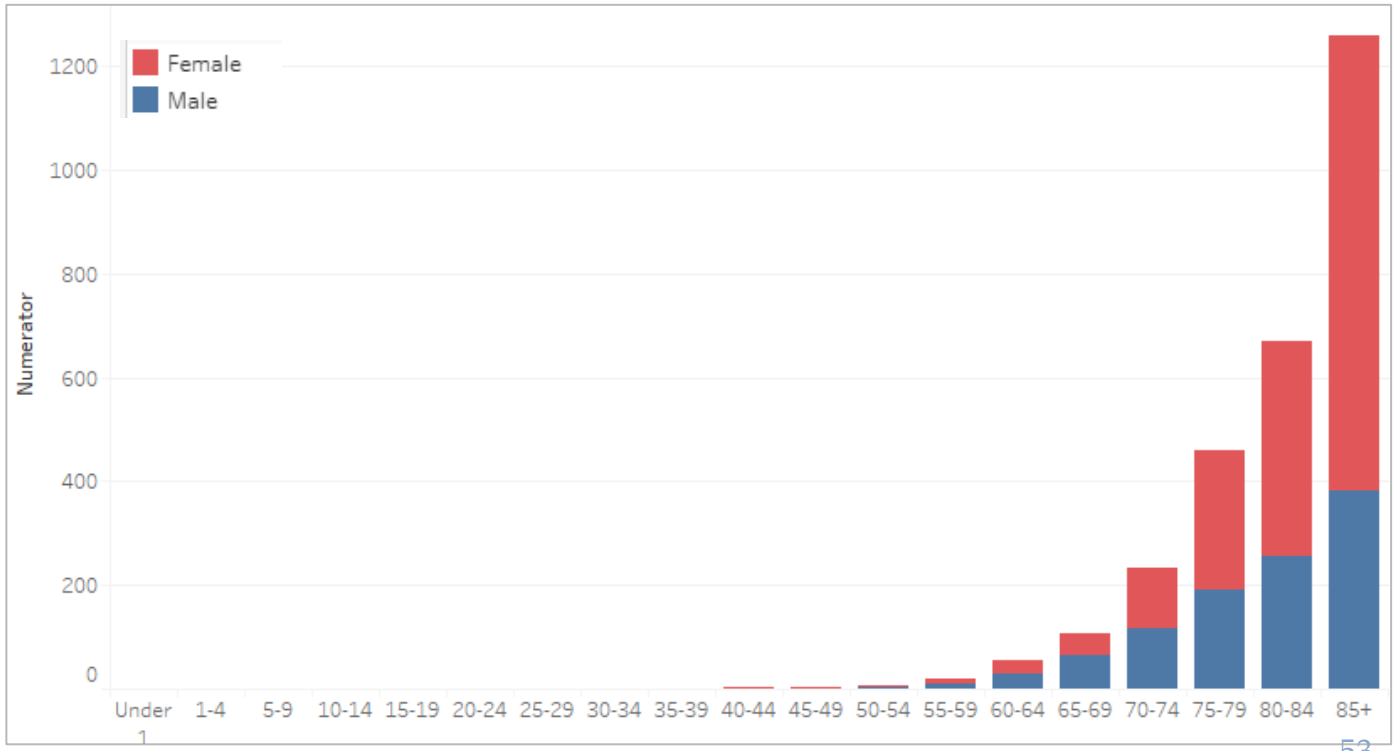
Nearly 50% of the female dementia patients are over 85 years old compared to 36% of the male patients. This means that 45% of the total dementia patients over the age of 85 years old. This age group is set to grow substantially over the next 20 years, and is due to make up over 10% of the West Wales population by 2040. Recent studies show that the incidence of dementia is not increasing substantially but due to increased life expectancy and better outcomes for care, perveance will continue to increase.

Mortality from dementia became the leading cause of death in the UK in 2015 and has continued to displace other causes of death. Pre-Covid (2020) it represented 12.7% of deaths and that number had grown yearly

The prevalence across the whole population of patients on the QOF register diagnosed with dementia is just over 0.7%. However, the prevalence in the over 60s (people on the register/population in the age group) is 2.3%. Young onset dementia is defined as those under 65 being diagnosed.

These represent a very small number of GP diagnosed cases but potentially a larger portion of the unmet and undiagnosed need

People over 60 represent around a third of the population and 98.9% of the registered dementia patients in West Wales



Source: GP QOF

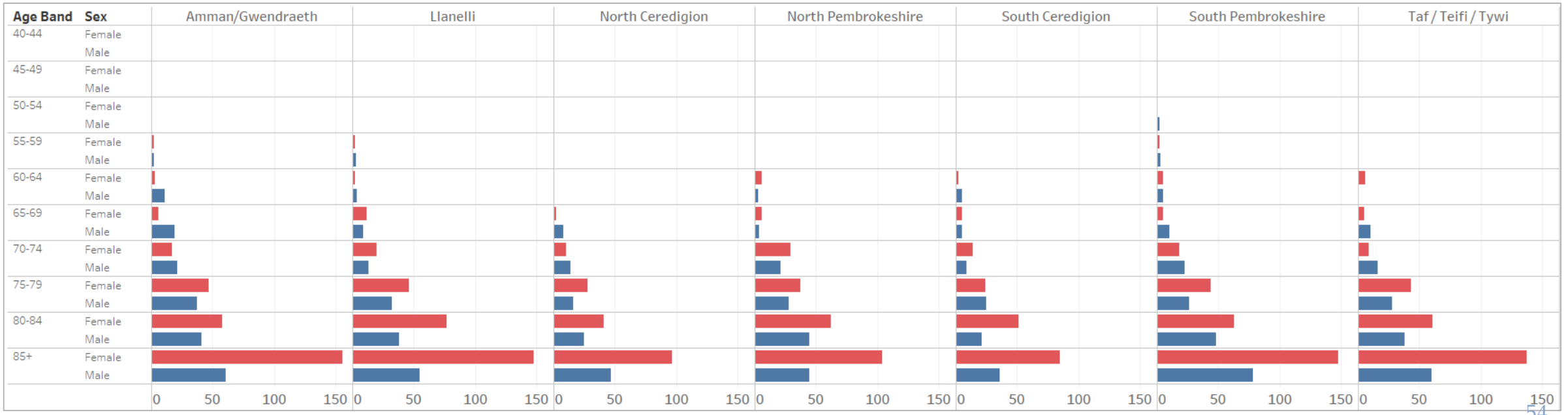
Dementia by cluster

Carmarthenshire has the largest population of the 3 counties across West Wales, it has around 49% of the whole population and 46% over the 0ver 65s, with 24% of its own population over 65 years old. They have 48% of the dementia diagnosis. It is also the most rural area of the three counties.

Pembrokeshire GPs have a recorded population with dementia diagnosis of around 870 patients, which represents around 31% of the dementia diagnosis in West Wales. As a county they have 32.5% of the population and 34% of the over 65 population. The over 65 population represents nearly 27% of the total population in Pembrokeshire. However, by 2040 the growth for Pembrokeshire will be 6.6%

Although Ceredigion's population is set to decrease overall, the over 65s is set to increase by over 4% in the next 20 years.

The below graphic shows the male and female actual numbers by cluster and as you can see, the three Carmarthenshire clusters have very high numbers, comparatively, in the female over 85s category. Notably South Pembrokeshire also has high numbers of both male and female over 85s diagnosed with dementia

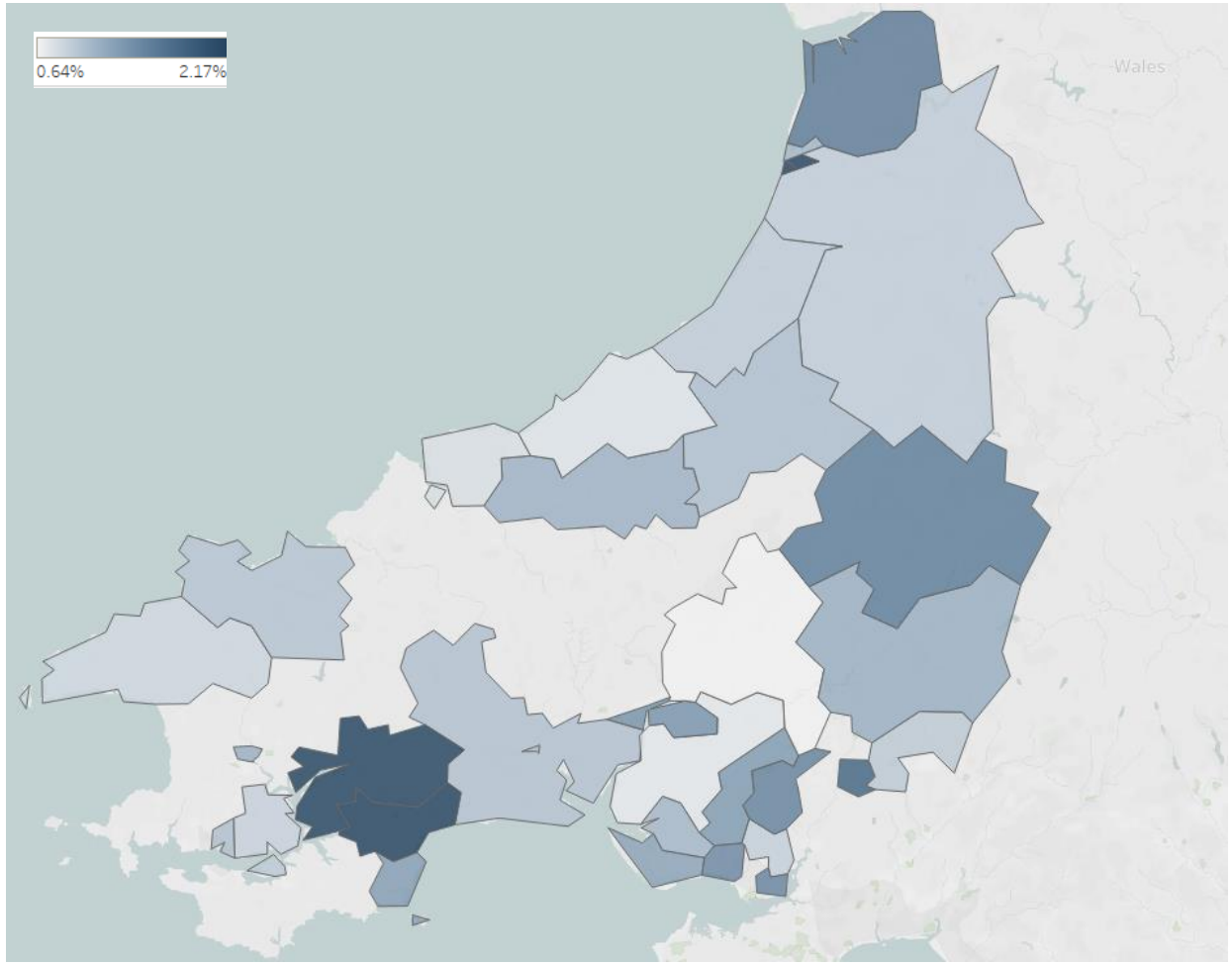


Source: GP QOF and ONS

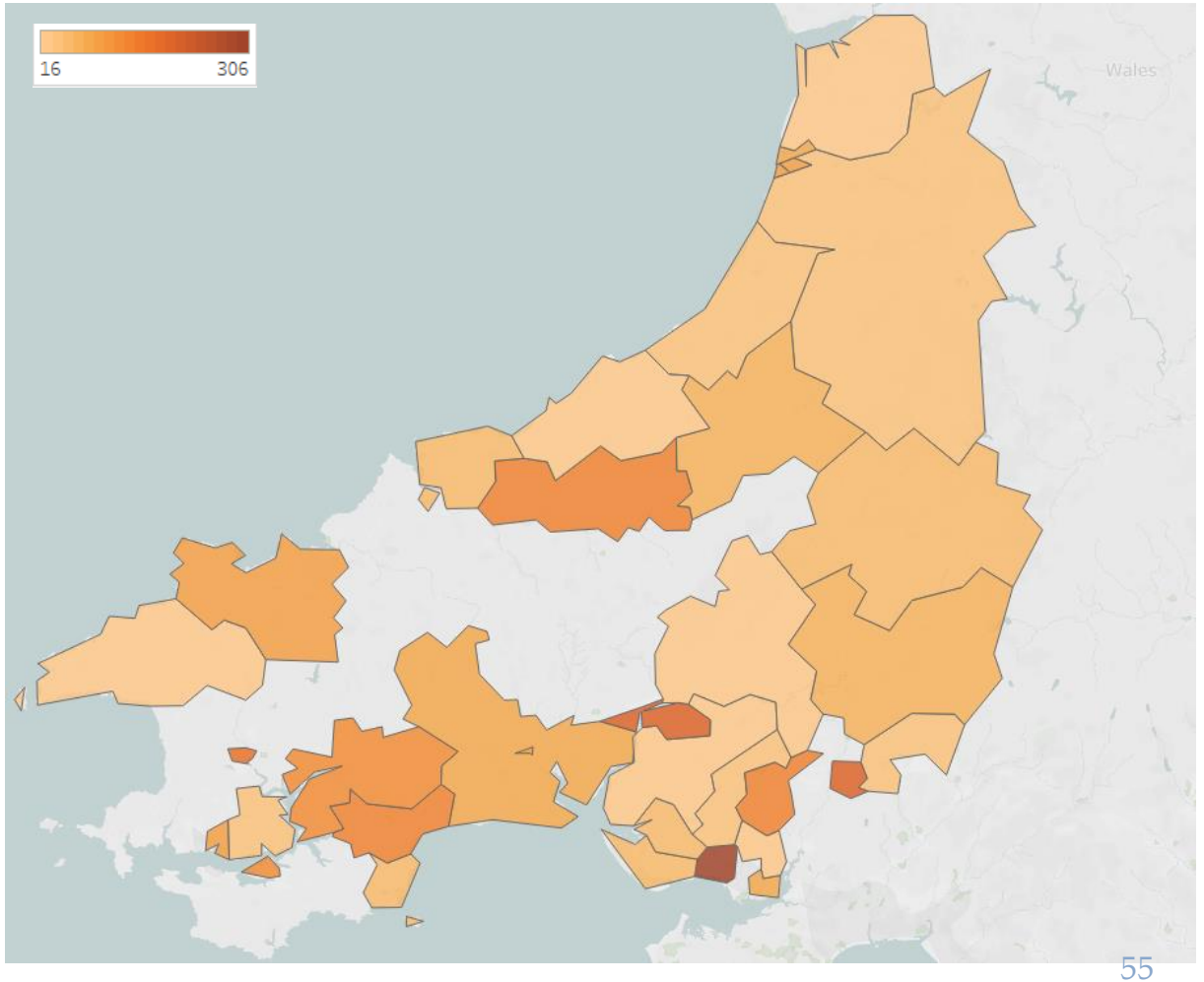
Map

Lower Layer Super Output Areas (LOSA) data for patients was not available and so the below information shows the pressure for the GP practices at a Middle Layer Super Output Area (MOSA) level which is why there are gaps.

Proportion of over 40s population based on practice list, by MOSA of practice location

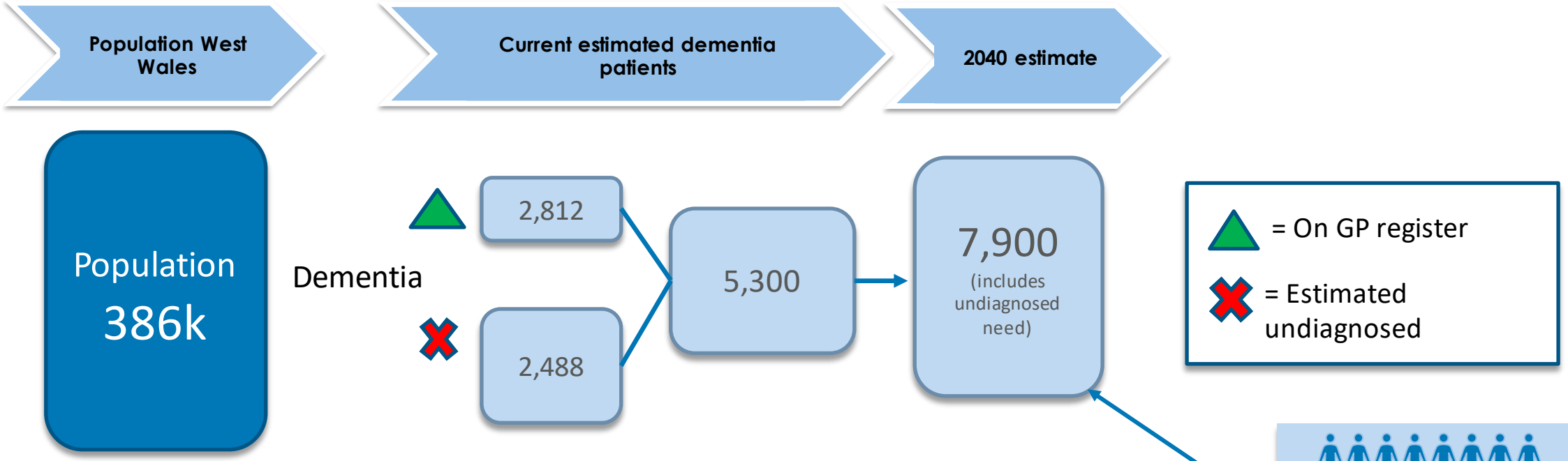


Total diagnoses population based on practice list, by MOSA of practice location



Dementia- prevalence

The chart below shows the current registered dementia population and the possible undiagnosed level; it then predicts, based on both the undiagnosed rate and population growth, the possible number of patients living with dementia across West Wales by 2040. It is important to note that the impact of COVID-19 on the diagnosis and incidence rate of dementia is still unknown. There is concern that, in some cases, COVID-19 causes damage to the brain and long term this could lead to increased risk of developing dementia*



- → Prevalence on the GP registers is currently just under 1% overall
- → There is a likely diagnosis gap of around 50%
- → The above calculates, at a high level, the possible actual prevalence based on population growth and application of the diagnosis rate
- → The prevalence as a rate could be as high as 2% by 2040, based on the growth in the over 65 population

***Reference**: "The chronic neuropsychiatric sequelae of COVID-19: The need for a prospective study of viral impact on brain functioning" - Gabriel A. de Erausquin et al*

Health board comparison

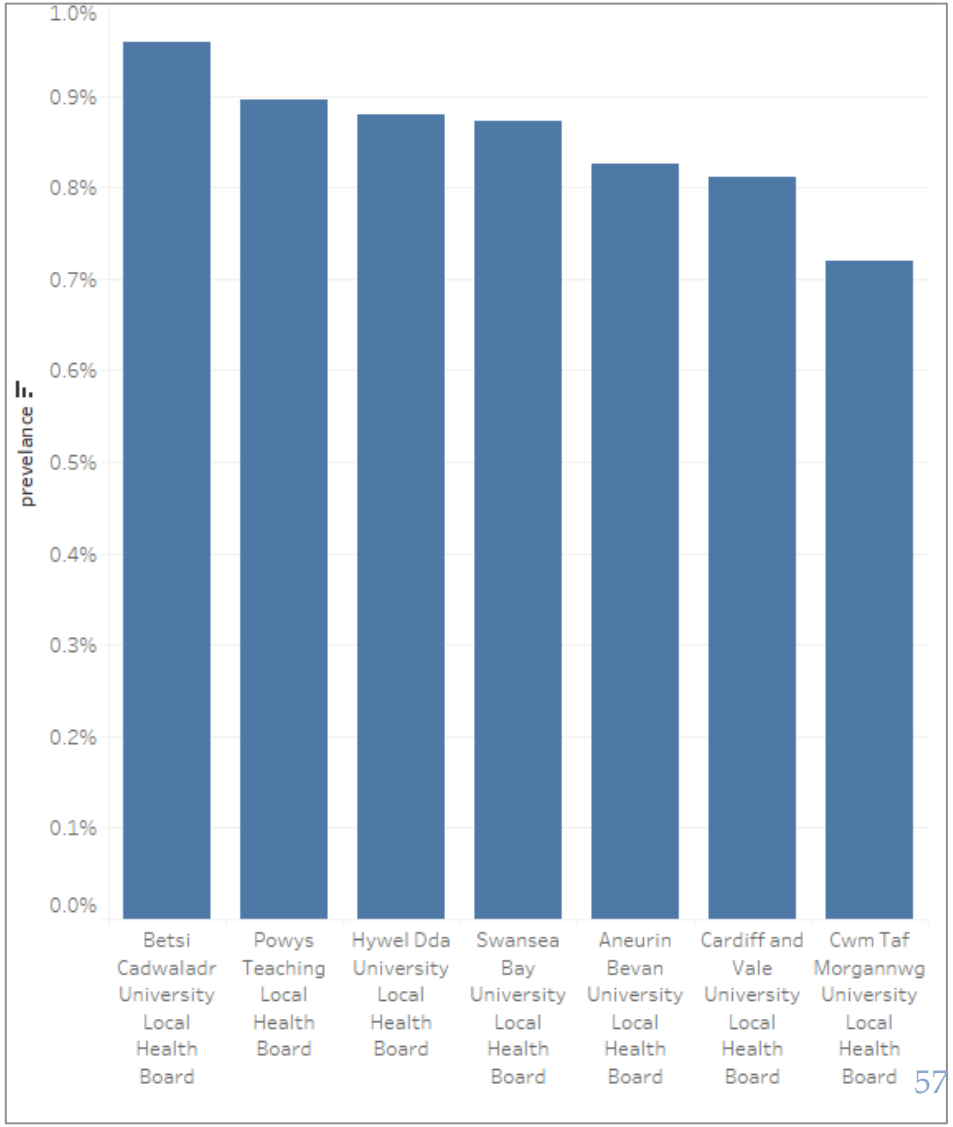
The graph to the right shows the prevalence rates for dementia recorded in the GP registers (according to QOF definitions). Note, this is likely to be a lower than actual prevalence rate due to using GP registered population from the GP system as the denominator (and not resident population, it also includes all age groups)

However, the important thing to note is the differences rather than the numbers. West Wales are the 3rd highest and they are slightly above the Wales average (circa 0.87% compared to 0.85%)

Numbers of patients on dementia register by sex and UHB

	Aneurin Bevan University Local Health Board	Betsi Cadwaladr University Local Health Board	Cardiff and Vale University Local Health Board	Cwm Taf Morgannwg University Loca..	Hywel Dda University Local Health Board	Powys Teaching Local Health Board	Swansea Bay University Local Health Board
Female	2,560	3,492	2,189	1,659	1,753	622	1,692
Male	1,500	2,048	1,166	985	1,059	346	1,047

Dementia GP register prevalence (among adult population)

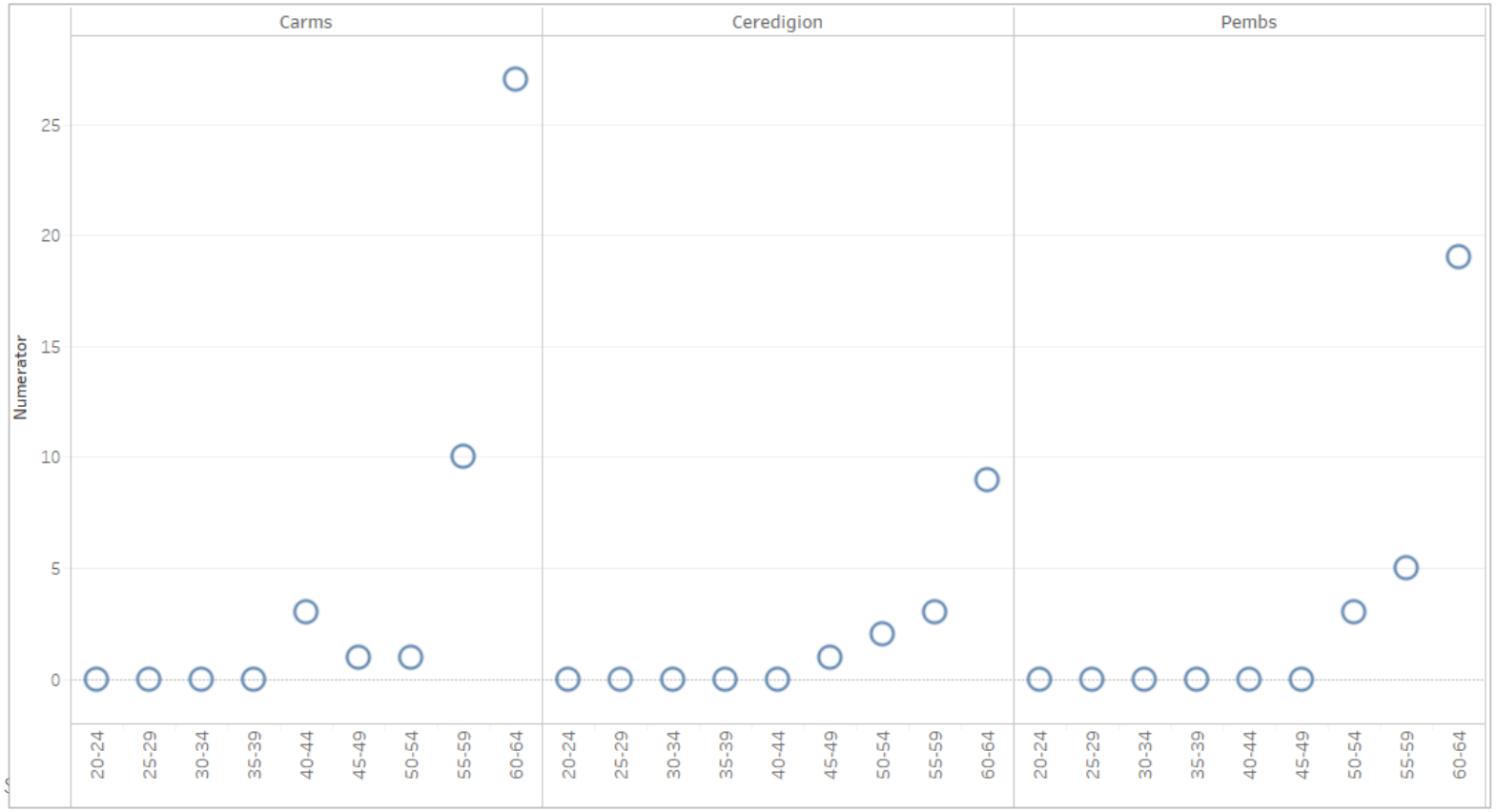


Young onset

Young onset dementia is the onset of dementia when a person is under 65 years old. Across West Wales there are 84 patients on the registers who are under 65 years old. Of those, 55 are in the 60-65 year age group. This gives West Wales a rate of 0.04% across the population in the adult population, which is very similar to the rate seen across Wales registers nationally.

There are 5 patients on the GP registers who are under 50 years old. There are under 30 in Wales as a whole (with a formal, GP registered diagnosis). Again, the prevalence rates across West Wales are higher than that of Wales (around 0.0025%)

Young Onset Dementia by age and cluster



10. Appendix 2: Feedback From Initial Structured Interviews

Stakeholder Engagement

The first phase of the development of this strategy took place January through to May 2021. Attain were initially commissioned by Carmarthenshire County Council on behalf of the WWCP to carry out a review of the ICF Dementia Investment Plan along side the development of a high – level dementia strategy vision and service model pathway across the West Wales region. The initial work was well supported by WWCP who worked with Attain to codesign a high-level draft dementia strategy. Stakeholders from across the region worked very hard to provide local knowledge and insight, through structured stakeholder discussions. The themes stemming from the initial interviews have been summarised where possible on the following pages. Theme form the second phase of work is summarised earlier on in the strategy.

Many thanks to those who engaged in this first phase of work:

Name	Title	Additional Staff
Rhian Dawson	Hywel Dda UHB & Carmarthenshire County Council - County Director Carmarthenshire	Emails sent 25/03 and 12/04
Jina Hawkes	Hywel Dda Health Board - General Manager Community Primary Care - Ceredigion	
Sonia Hay	Hywel Dda UHB - General Manager Community & Primary Care -Pembrokeshire	Charlotte Duhig, Ceri Griffiths plus 2 others
Rebecca Jones	WWCP Programme Manager for Workforce development	
Sue Leonard	CEO PAVS	Cherry Evans Sophie Buckley
Elaine Lorton	Hywel Dda UHB County Director Pembrokeshire	
Peter Skitt	Hywel Dda UHB - County Director Ceredigion	
Alex Williams	Head of Integrated services Carms	Plus Carms colleagues
Neil Mason	Hywel Dda UHB - Service Manager Older Adults Mental Health	Plus Admiral Nurse
Graham O'Connor	(Hywel Dda UHB - Consultant Psychiatrist)	
Donna Pritchard	Head of Adults Ceredigion Council	Ellen James, Sian Howys, Nerys Lewis
Claire Sims	Hywel Dda UHB - Head of Occupational Therapy	Plus Karen Shearsmith-Farthing
Becca Stilwell	Clinical Psychologist	Email sent 15/04/21

The themes stemming from the interviews with stakeholders have influenced the development of the service model pathway and the recommendations within this report.

Main themes	What works Well	What could be improved	What elements are missing	Joined up services
A clear regional strategy, vision and service model is needed and long term funding to deliver the services is needed	3rd sector dementia connector role has brought together other dementia focused roles now operating as an MDT	Consultants trained to be able to support people with dementia	Informal carers getting exhausted - could be prevented if they have the right support	Dementia is so wide - it is across the whole community and it really needs to be part of day to day planning and development
The overarching thing not addressed is base line wrap around the person, a co-ordinator throughout their journey	New Admiral Nurse service sitting with social care - providing support, bringing other professionals in team around the person	There is a need for **all** GPs to take the responsibly for onward prescribing of dementia	No centralised overview of GP dementia registers	Organisations now need to play their part to form a joined up integrated approach - not easy for West Wales
There is no coherent pathway and a lack of person centred care/understanding of dementia	Some good examples – Delta Connect, fulfilled lives - person centred domiciliary care, Ceredigion - come up with good solutions - real team feel	GPs/AHPs could be making straight forward diagnosis. MH team should be focusing on specialist diagnosis	Programme management of West Wales dementia services through the WWCP, service evaluation and performance reporting	Lots of handovers between services - difficulty with the long term care - where does dementia sit? No one service has the capacity to manage this large cohort
Attribution that dementia is a MH issue so if someone presents with challenging behaviour they call MH	Alzheimer's provide pre-diagnostic support following referral - people go directly to face to face support rather than a call centre.	National system feedback on hospital care can be adapted for PLWD and their carers to provide feedback on **all** our services	Requirement to have EoL conversations earlier. Some professionals reluctant to enter in ACP conversations	The service vision and model needs to ensure that services are easy to access and joined up

The themes stemming from the interviews with stakeholders have influenced the development of the service model pathway and the recommendations within this report.

Communication	How people are diagnosed	How people access services	Workforce and Training	Use of technology
Dementia wellbeing in the acute hospitals supporting reasonable adjustments for those admitted. Part of the ward MDT – about to be evaluated	Local Authority carers assessment is not dependant on a diagnosis but you still hear of it	Social care domiciliary care, respite care - harder to access and less secure postcode lottery going on to access	The regional dementia wellbeing team about to be launched will provide training to upskill staff and a specialist MDT approach for complex cases	In alignment with best practice, the use of technology should be central to the delivery of dementia services
Currently too many handoffs not joined up in anyway - need to have some co-ordination and case management.	Need for earlier identification and diagnosis in primary care. Need to fast track dementia diagnosis in line with CHC assessments	Where do people lives sit? Holistic picture - need to include the needs of the carers collated within the record of the person living with dementia.	People providing care need to be able to spot dementia and have skills to support - regular training refreshers are needed	Delta connect trying develop care so the person can stay at home
Develop structure for services to communicate better with each other/to share information - what is available in the community - feels very fragmented.	Consider what is the purpose of the diagnosis? Treatment? Medication? Delaying the inevitable? Respite, carers support?	There is an opportunity for a central point of access through the Delta Wellbeing service which is provided regionally	GPs require training to detect the early signs of dementia and physical issues in the advanced stages. Trainee MH nurses need training in dementia	The Wellbeing Team is working with Delta connect - trying to skill up the crisis team to stop people having to go into hospital
FIRST OF ITS KIND - OT's are working in Scotland and are providing journey through dementia - protocolled interventions which will be evaluated	Belief that it can only take place in MAS setting - some patients get diagnosed in hospital. Need an MDT approach to diagnose in community	Need to review dementia navigators, community commentors, social prescribing type roles to avoid duplication and align them across the system	A lack of knowledge, confidence and skill in staff/services recognising that people with dementia and their carers use multiple services	The Wellbeing team is working with @learning Wales to make the training more accessible. Mindful that eLearning training doesn't give people tools

11. Appendix 3: Approach to managing the programme of work

Project Requirement	Progress	Key Accomplishment
Review existing regional governance to ensure robust, multi-agency ownership of the ICF Plan, its delivery and evaluation	✓	This report provides a suggested programme outline

What does good programme management look like?

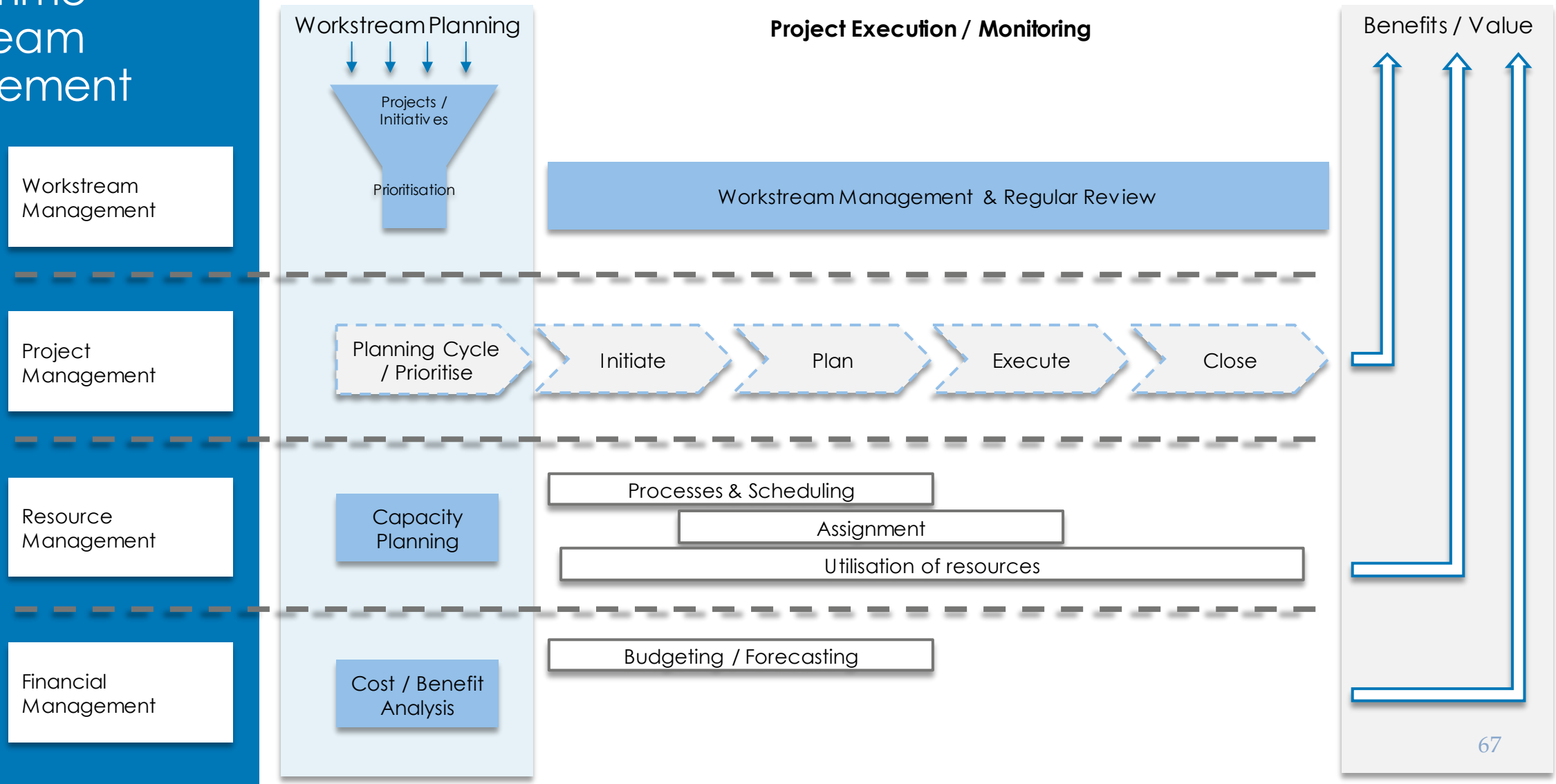
The components of a good programme (1)

	Vision, Leadership & Culture	Programme Governance	Stakeholder Management and Communication	Planning and resourcing
What good looks like	• Clear shared vision owned by all partners • Joined up leadership fully engaged • Vision and strategy are aligned with partners' organisational strategies and relevant regional / national strategies	• Clear governance structure in place that includes input at the right level for decision making and managing risks/issues • Clear process in place for escalating risks, issues and opportunities • Lean structure; time is used effectively, with a balance between discussion and action • Programme team have a clear understanding of roles and responsibilities • Patient / public engagement embedded in programme governance • Clinical leadership embedded in programme governance	• Stakeholder mapping and communications plans in place • Key stakeholder relationships are managed proactively • External communications are targeted at relevant audiences and accessible language / communication formats are used • Internal communications to keep programme team informed, support team dynamics • Successes are celebrated internally and all areas of the programme contribute to case studies and good news stories for external use	• Robust overall business case for the programme in place and agreed by partners, with review points in place to establish ongoing viability • Each workstream has a clear plan, setting out what will be delivered, how and when • Interdependencies have been mapped • Resources required to deliver the programme have been mapped and investment agreed • OD requirements mapped and strategy in place for coordinated delivery
Tools and products	• Vision / mission / values statement • Memorandum of Understanding / partnership agreement • Outline Business Case	• Programme Governance Structure Chart(s) • Terms of Reference • Meetings forward plan • Programme team organisation chart • Roles / responsibilities matrix • Reporting and risk/issue escalation processes • Templates for meeting agendas, notes and actions, highlight reports	• Programme Communications & Engagement Strategy / Action Plan • Stakeholder mapping tool • Internal communications process • Equality Impact Assessment process and documentation • Core set of programme documentation / presentations / branded templates for use with a range of audiences • Engagement tracker	• High level programme plan with milestones and critical dependencies • Detailed programme plan • PMO work plan • Recruitment and resourcing tracker (programme team) • Business case process, template and guidance • Financial plan

The components of a good programme (2)

	Outcomes and Benefit Tracking	Risk and Management	Programme Support	Financial Management
What good looks like	• Financial and non-financial benefits of the programme have been clearly articulated (covering activity shift, clinical quality and patient experience) and tested out with key stakeholders • Robust methodology in place to track benefits across all work streams • Baseline data captured • Outcome measures are targeted to enable monitoring of specific interventions – to see whether a change is effective • Existing data sets and reporting are utilised wherever possible to minimise reporting burden (lean approach)	• Key risks to delivery of the programme have been mapped and mitigating actions identified • Clear processes are in place for identifying and tracking risks, with levels of escalation • Robust, consistent documentation used across the programme to support proactive risk management and provide an audit trail • Programme risk register is maintained and reviewed regularly with evidence of following up mitigating actions recorded and followed through	• Information is well managed and easy to find, e.g. contact list, filing structure, protocols in place for maintaining an audit trail • Change control in place for core documents/tools • PMO team is able to support operational staff / work streams by reducing the documentation burden • PMO advises and supports programme team / delivery leads; skills development, quality improvement • Quality assurance is in place for key deliverables	• Budget agreed for programme resourcing • Robust mechanisms in place for management of programme budget – budget setting, change control, monitoring, accounts payable, procurement
Tools and products	• Business Case/ Investment Appraisal • Benefits/outcomes framework, capturing key performance indicators, outcome measures, metrics etc) • Benefits realisation plan and tracking tool	• Programme risk and issue register • Risk management process and guidance	• Programme contact list • Information Management protocols and filing structure • Shared programme calendar / inbox	• Programme Financial management process / control • Programme budget

Proposed Delivery Approach: Programme Workstream Management



Contacts

Martin Wilson	martin.wilson@attain.co.uk	07710 744391
Su Gordon-Graham	su.gordon-graham@attain.co.uk	07717 035647
Adele Yemm	adele.yemm@attain.co.uk	07766 681051
Cherie Cope	cherie.cope@Attain.co.uk	07787 427341