Bwrdd Iechyd Prifysgol Hywel Dda University Health Board

CYFARFOD BWRDD PRIFYSGOL IECHYD UNIVERSITY HEALTH BOARD MEETING

DYDDIAD Y CYFARFOD: DATE OF MEETING:	29 July 2021
TEITL YR ADRODDIAD: TITLE OF REPORT:	West Wales Care Partnership: Draft Dementia Strategy
CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:	Alison Shakeshaft, Director of Therapies and Health Science
SWYDDOG ADRODD: REPORTING OFFICER:	Rhian Dawson, Integrated System Director, Carmarthenshire

Pwrpas yr Adroddiad (dewiswch fel yn addas)
Purpose of the Report (select as appropriate)

Ar Gyfer Penderfyniad/For Decision

ADRODDIAD SCAA
SBAR REPORT

Sefyllfa / Situation

The incidence of dementia in West Wales (and Wales in general) is expected to rise dramatically over the coming decades and should be a critical area of focus to realise improved outcomes for patients living with dementia and their families and carers. Furthermore, there are opportunities to reduce the risk of developing dementia by embedding population health preventative interventions.

The West Wales Care Partnership commissioned the development of a draft service vision, service model pathway and high-level strategy. The strategy will ensure that optimal and consistent standards and pathways of care and support are embedded across the Health Board and its co-terminus Local Authorities to ensure outcomes for our population at risk of developing dementia, or who are living with dementia, are enhanced.

The Board is asked to consider and approve the draft Dementia Strategy.

Cefndir / Background

Across the region, numbers of diagnosed cases are expected to nearly double, from 2,812 to 4,200. A likely gap in diagnoses of some 50% means that the true extent of people living with dementia and future prevalence is significantly higher.

The Dementia Action Plan for Wales 2018-22 sets out a strategy for Wales to become a dementia-friendly nation based on the rights of people with dementia to feel valued and live as independently as possible in their communities. The Plan recognises that a cross-sector, co-produced approach is required to provide effective care and support for people with dementia.

Furthermore, Welsh Government recently published the 'All Wales Dementia Care Pathway of Standards'. The aim of these standards is to improve dementia care for individuals and their carers by providing a clear pathway towards implementing effective standards within dementia care over the next two years.

In response to the demographic and related epidemiological challenge related to dementia, it is incumbent on the Health Board to ensure that optimal standards and practice are embedded in our planning and delivery. This includes ensuring that actions are in place that support reducing the risk of people developing dementia, facilitating early diagnosis of dementia and the provision of care and support for our population living with dementia and their families / carers.

Asesiad / Assessment

Following the publication of the Dementia Action Plan for Wales, the Health Board, as part of the West Wales Regional Partnership, was afforded annual financial support through the Integrated Care Fund (ICF) to implement elements of the plan.

Achievements to date include:

- Completion of a training needs analysis highlighting where additional education and support are needed to ensure that employees across the health, care and support sectors are able to recognise and respond appropriately to the needs of people with dementia and their carers. This will inform a comprehensive programme of training for staff in 2021-22.
- Appointment of 7 'Admiral Nurses' across West Wales, working in a variety of settings and providing people living with dementia and their families one-to-one support, expert guidance and practical solutions when challenges and difficulties arise.
- Establishment of a Dementia Wellbeing Team providing support to individuals and carers in a range of settings to reduce distress, often presenting as challenging behaviour in people living with dementia.

In December 2020, the West Wales Care Partnership appointed Attain consultants to work with us on the development of a regional Dementia Strategy and review our ICF programme, building on regional foundations and recognised best practice at a national and international level and helping ensure ICF and other resources are invested wisely. Attain have also developed a Palliative Care Strategy for the UHB and clear links have been identified between both models which need to be exploited moving forward.

As a first phase, Attain has developed a draft service vision, service model pathway and high-level strategy (Appendix 1) which is brought to the Board for approval. Once formally approved by all statutory partners, further development and co-design is required in order that the strategy, service vision and service model is owned by colleagues, people living with dementia (PLWD) 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 All-Wales Dementia Care Pathway Standards published by the Improvement Cymru Delivery Framework in March 2021.

The contract with Attain will be extended for 6 months from July 2021 to support completion of this next phase and finalisation of the strategy.

Argymhelliad / Recommendation

The Board is requested to **CONSIDER** and **APPROVE** the draft service vision, the service model pathway and high level Dementia Strategy.

Amcanion: (rhaid cwblhau) Objectives: (must be completed)	
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	N/A
Safon(au) Gofal ac Iechyd: Health and Care Standard(s): Hyperlink to NHS Wales Health & Care Standards	1.1 Health Promotion, Protection and Improvement 3.1 Safe and Clinically Effective Care 5.1 Timely Access 6.1 Planning Care to Promote Independence
Amcanion Strategol y BIP: UHB Strategic Objectives: Hyperlink to HDdUHB Strategic Objectives	3. Growing older well 4. Improve the productivity and quality of our services using the principles of prudent health care and the opportunities to innovate and work with partners. 2. Living and working well
Amcanion Llesiant BIP: UHB Well-being Objectives: Hyperlink to HDdUHB Well-being Objectives Annual Report 2018-2019	2. Develop a skilled and flexible workforce to meet the changing needs of the modern NHS 4. Improve Population Health through prevention and early intervention, supporting people to live happy and healthy lives 8. Transform our communities through collaboration with people, communities and partners

Gwybodaeth Ychwanegol: Further Information:	
Ar sail tystiolaeth: Evidence Base:	All Wales Dementia Action Plan All Wales Dementia Care Pathway of Standards
Rhestr Termau: Glossary of Terms:	N/A
Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Cyfarfod Bwrdd Iechyd Prifysgol: Parties / Committees consulted prior to University Health Board:	N/A

Effaith: (rhaid cwblhau) Impact: (must be completed)	
Ariannol / Gwerth am Arian: Financial / Service:	As referenced within the West Wales Care Partnership draft Dementia Strategy
Ansawdd / Gofal Claf: Quality / Patient Care:	As referenced within the West Wales Care Partnership draft Dementia Strategy
Gweithlu: Workforce:	As referenced within the West Wales Care Partnership draft Dementia Strategy
Risg: Risk:	As referenced within the West Wales Care Partnership draft Dementia Strategy

Cyfreithiol: **Legal:**	As referenced within the West Wales Care Partnership draft Dementia Strategy
Enw Da: **Reputational:**	As referenced within the West Wales Care Partnership draft Dementia Strategy
Gyfrinachedd: **Privacy:**	As referenced within the West Wales Care Partnership draft Dementia Strategy
Cydraddoldeb: **Equality:**	As referenced within the West Wales Care Partnership draft Dementia Strategy

DRAFT West Wales Care Partnership (WWCP) Dementia Strategy

Attain
Improving health and wellbeing

June 2021
V8_0**DRAFT**

Contents

1. Executive summary

Background

In December 2020, the WWCP appointed Attain to undertake the development of a regional dementia strategy and service model pathway of care. Alongside this work, in order to align funding with the new service pathway, Attain were asked to carry out a review of the regional ICF dementia projects and to provide a steer as to what services should continue to be funded, as well as provide an indication as to any additional initiatives that should be undertaken during 2021/22. At the point of writing this high-level strategy, future government funding for dementia is not fully known. The review takes place in the current climate where:

- There is 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 regions across Wales covering the period April 2021 – March 2023.

Prior to the implementation of the Framework, Attain has developed this **a draft service vision, service model pathway and high-level strategy**. Once formally approved by the WWCP, further development and co-design is required so that the strategy, service vision and service model is owned by colleagues, people living with dementia (PLWD) 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
- **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. Review the current ICF Dementia Plan in anticipation of the overarching strategy and deliver plan.

- Review existing regional governance to ensure robust, multi-agency ownership of the ICF Plan, its delivery and evaluation

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 high-level strategy, vision and service model pathway based on best practice. The strategy also includes recommendations in relation to deployment of existing funding however further funding allocation is not known at this time.
- This strategy includes a proposed programme and governance structure which fits with the Welsh Government and Regional structures
- This strategy includes a summary of current and future population demand and prevalence. Information relating to the impact of COIVD upon those with dementia is not available at this stage
- Stakeholders have identified that COVID-19 has impacted timely diagnosis due to late presentations

2. Review of the current ICF Dementia Programme Plan :

- A review has been carried out with the Regional Programme Lead and a report has been developed following the review which includes the proposed approach to programme management

3. Stakeholder engagement and high-quality proposals:

- We have worked with multiple stakeholders across the region however in this initial first stage, people living with dementia (PLWD) and their carers were not included nor were front line staff. N.B. It will be important to also capture the views of Pembrokeshire County Council as they too missed the opportunity to contribute to this phase

Key Recommendations

1. Ownership of strategy, vision and service model pathway

- Once formally approved by the WWCP, further development and co-design is required so that the strategy, vision and service model pathway is owned by colleagues, PLWD and their carers across West Wales
- WWCP adopt the proposed governance structure and recruit a Regional Dementia programme manager
- The strategy, vision and service model pathway should be reviewed once information is available regarding the impact of COVID upon those with dementia and their carers
- The waiting time for diagnosis should be reviewed and monitored; solutions should be found to address the waits

2. ICF Dementia Plan:

- The report produced makes a series of recommendations in relation to continued funding for services in line with best practice, the All-Wales Dementia Action Plan and the new Welsh Dementia Standards.
- The next phase of developing the WWCP dementia strategy should include recommendations for future funding in line with the new agreed service model pathway

Best practice in 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 everybody's business, it is important to understand that there is a need 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 initiatives 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

Population projection of those with dementia in West Wales

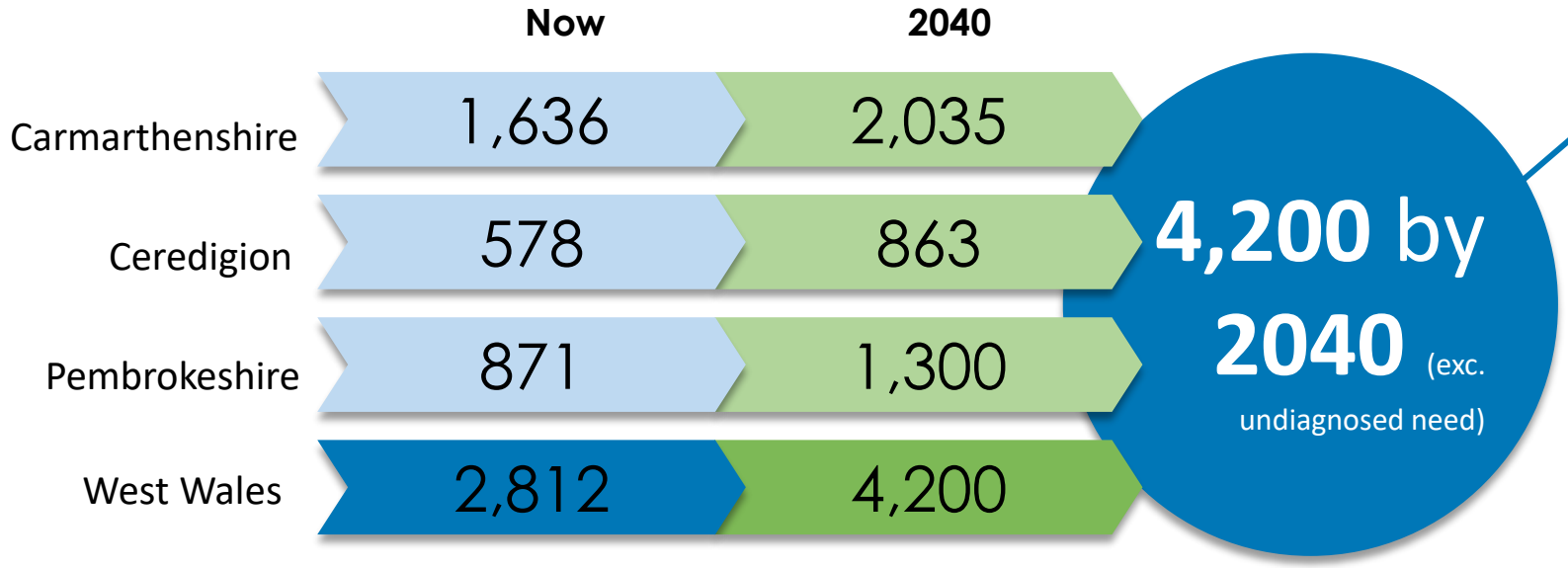
Attain

1 in 6

Alzheimer's Society UK estimates dementia affects one in six people aged 80+.

West Wales records show 1 in 10 over 85. Alzheimer's Research estimates that the diagnosis rate* is 53% across Wales. Suggesting an unmet need across Hywel Dda of 2,400 patients

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



To put this into perspective…

This is equivalent to everyone in Cardigan living with dementia.

N.B.

→ Prevalence on the GP registers is currently just under 1% overall

→ There is a likely diagnosis gap of around 50%

*The diagnosis rate is the number of diagnosis compared to the estimated actual prevalence)

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:

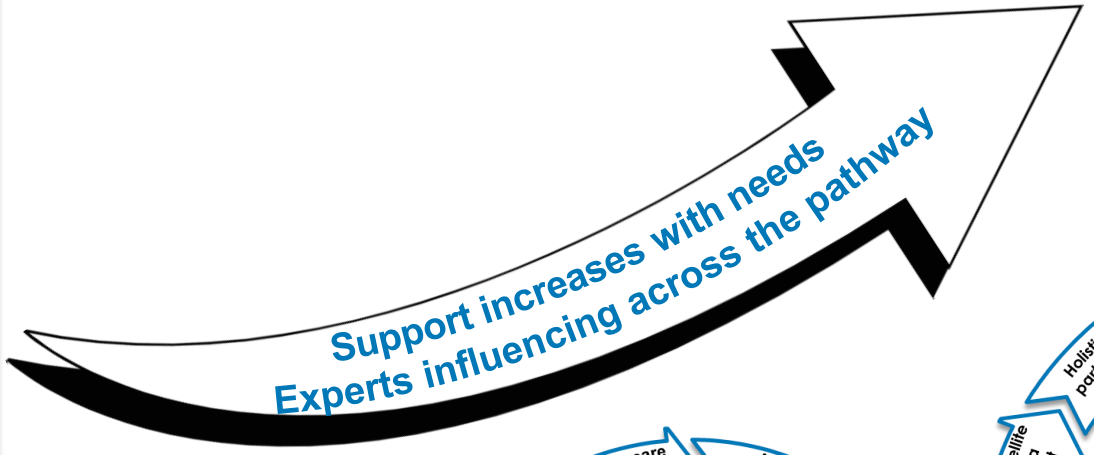
- Clear **regional dementia vision, strategy** and **service model** in line with best practice
- Develop **effective** professional and clinical leadership and **governance** to ensure the service model and **new roles** are designed in line with best practice and **are part of the whole health and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

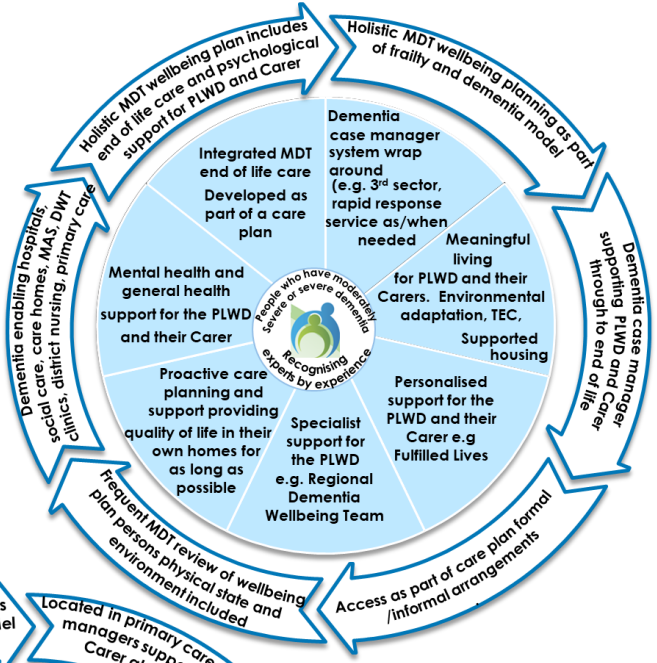
- **Joint commissioning** for **integrated care,** ensuring **equity** of **access** and **provision across West Wales**
- **Optimise the use of estate** - build on localities and **provide support closer to home** e.g. local meeting places/hubs where people can connect
- **Adapting IT** so that it reflects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

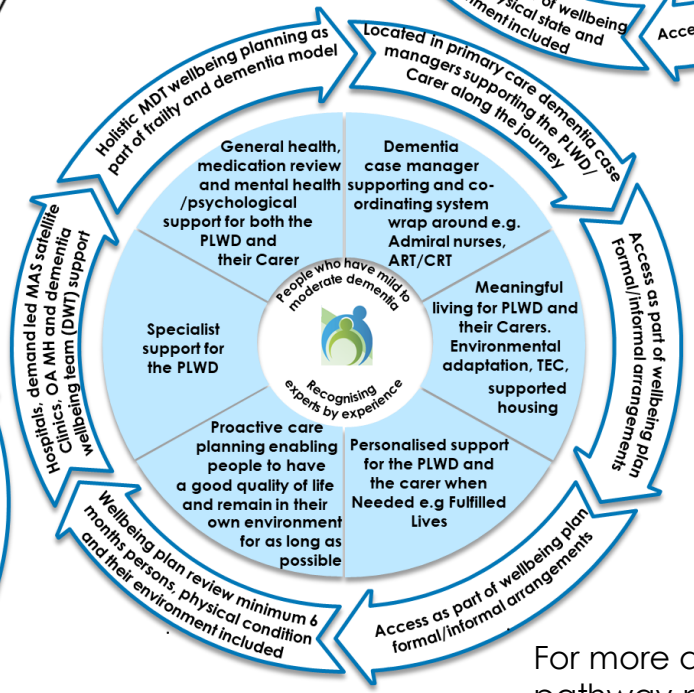
- New ways of working to expand the capacity of the Good Work training framework and **new workforce roles** e.g. **Dementia care co-ordinators/case managers**
- **Using technology** to **empower PLWD** and their **carers** and our **staff**.
- **Commissioning** and provision of **primary care services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

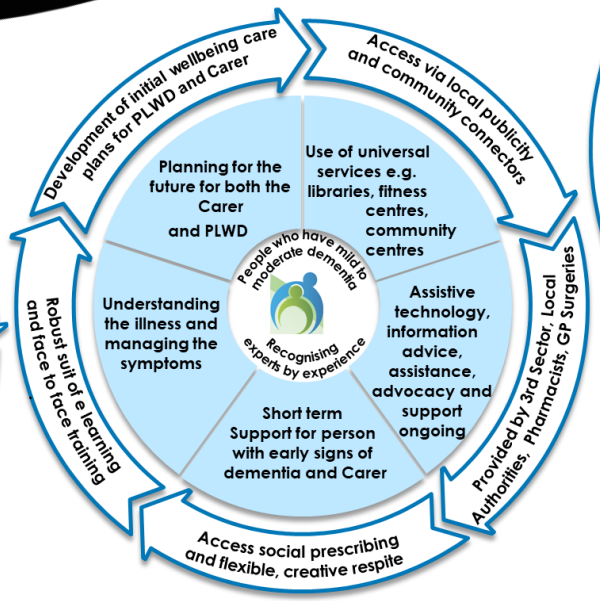
What good looks like for West Wales – The draft dementia wellbeing pathway

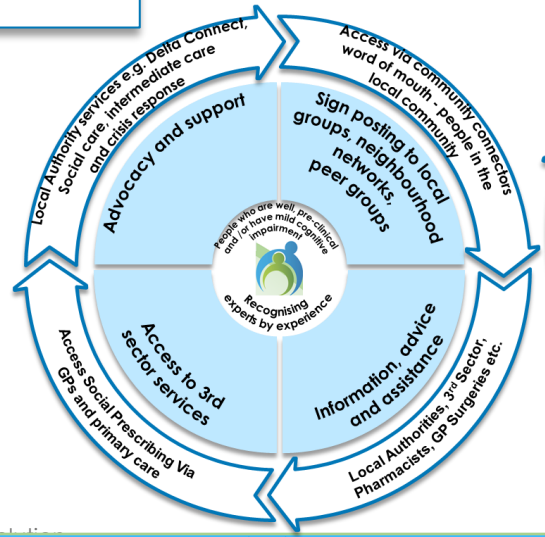
- This draft model, illustrates a new more joined up way of providing services. It is based on best practice and existing services within West Wales. The model requires further co-design with frontline staff, PLWD and their carers
- The service model should be underpinned with an agreed set of service delivery principles which need to be to be developed

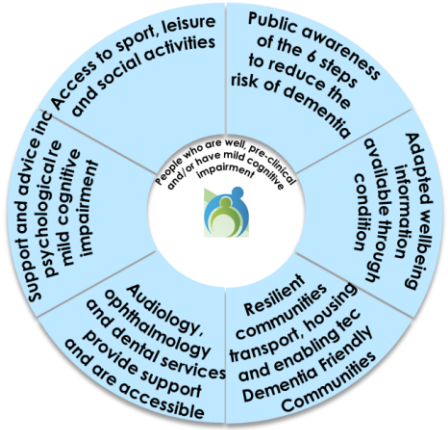










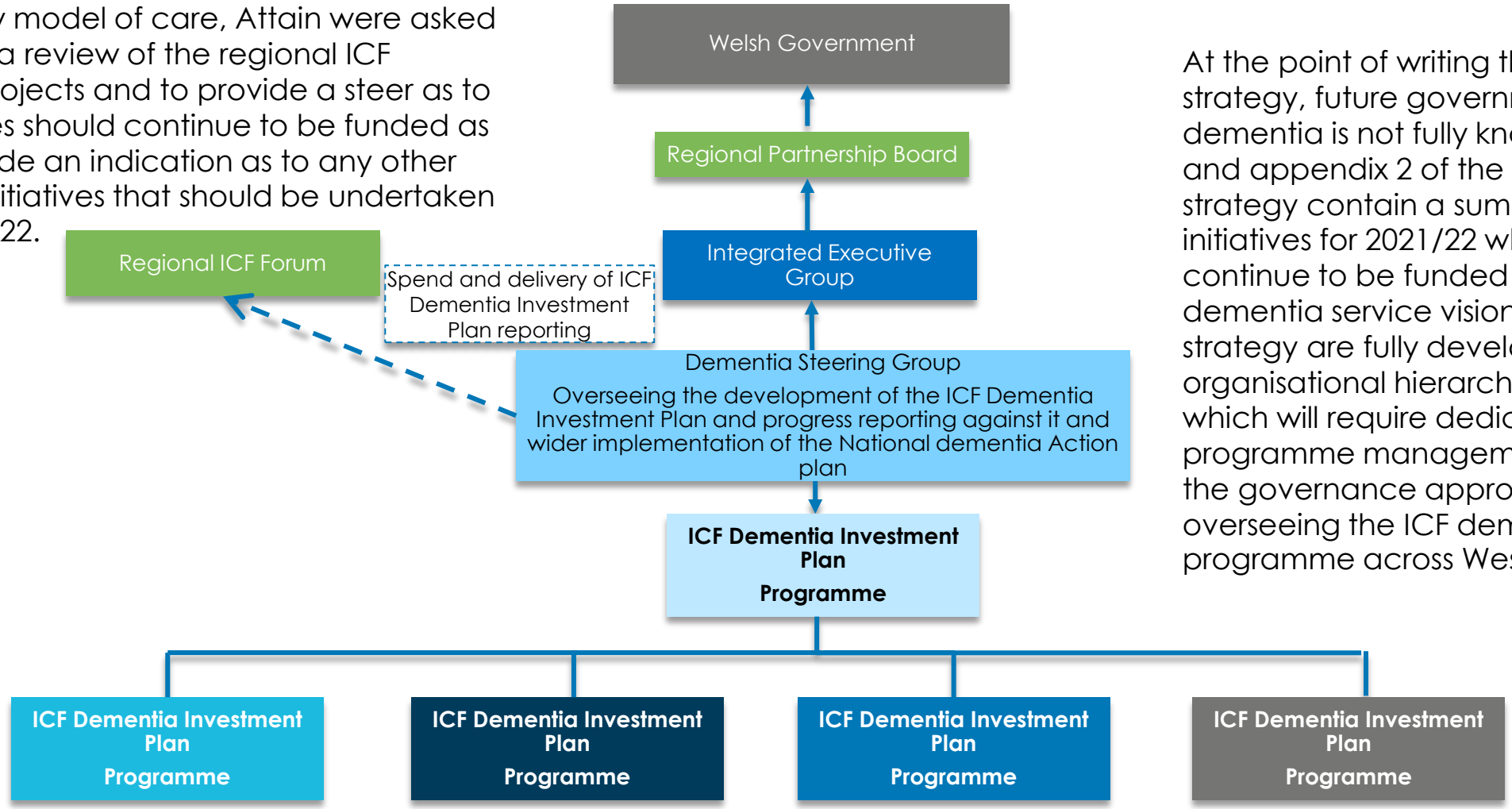


For more detail on the pathway please see section 6 of the main draft strategy

Under pinned by access to assistive technology, training - Implementation of the Recognition and Good Work Frameworks

Proposed Integrated Care Fund (ICF) Dementia Programme Governance Arrangements

Alongside this work and in order to align funding with the new model of care, Attain were asked to carry out a review of the regional ICF dementia projects and to provide a steer as to what services should continue to be funded as well as provide an indication as to any other additional initiatives that should be undertaken during 2021/22.



At the point of writing this high-level strategy, future government funding for dementia is not fully known. Section 7 and appendix 2 of the high-level strategy contain a summary of project initiatives for 2021/22 which will continue to be funded while the draft dementia service vision, model and strategy are fully developed. The organisational hierarchy to the left, which will require dedicated programme management, describes the governance approach to overseeing the ICF dementia programme across West Wales.

Next steps

Delivering the programme:

- Agree the rationale to continue funding during 2021/22 as outlined in section 7 of the high-level strategy
- Identify resource to set up and manage the programme of work across partners
- 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

Developing the strategy:

- Further co-design of the draft vision and service model pathway with frontline staff, PLWD and their carers through a series of workshops, surveys and focus groups
- Finalise the vision and service model pathway and socialise them so all partners are aware of the direction of travel for dementia services within West Wales
- Update the programme plan with the new service developments required to deliver the vision and service model 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

2. Population needs analysis

For more information on the population analysis please see appendix 1

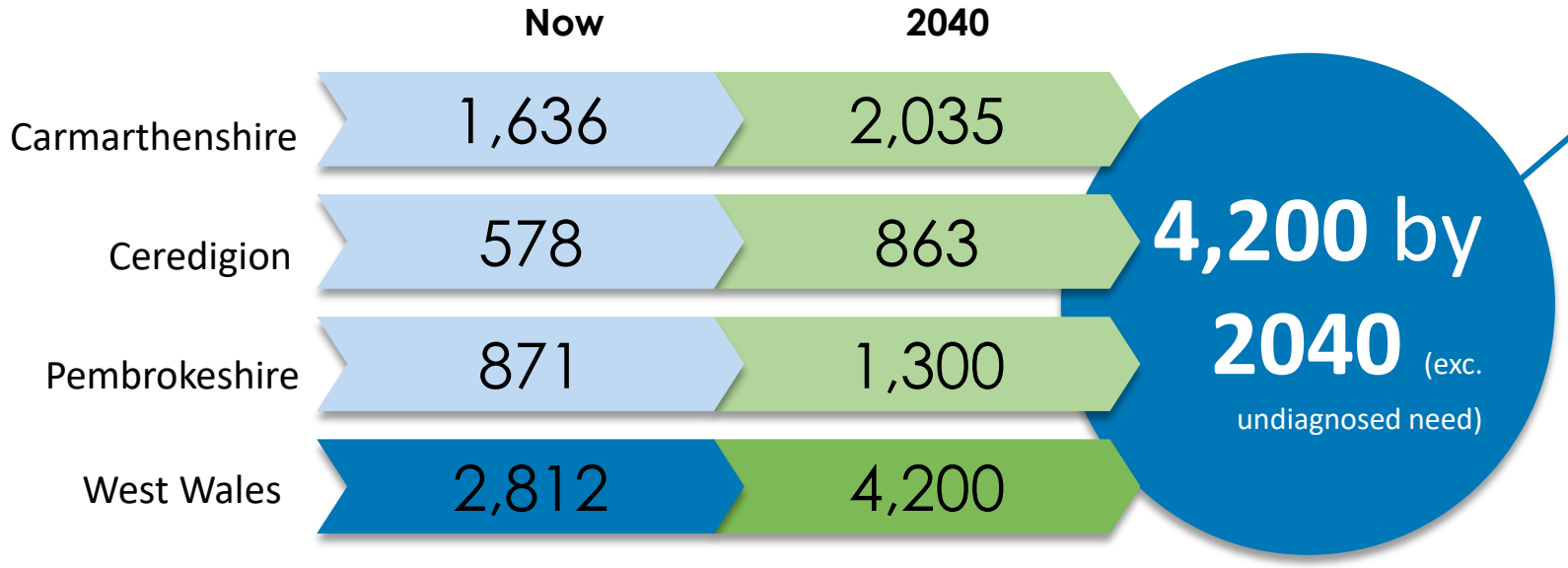
Population projection of those with dementia in West Wales

1 in 6

Alzheimer's Society UK estimates dementia affects one in six people aged 80+.

West Wales records show 1 in 10 over 85. Alzheimer's Research estimates that the diagnosis rate* is 53% across Wales. Suggesting an unmet need across Hywel Dda of 2,400 patients

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



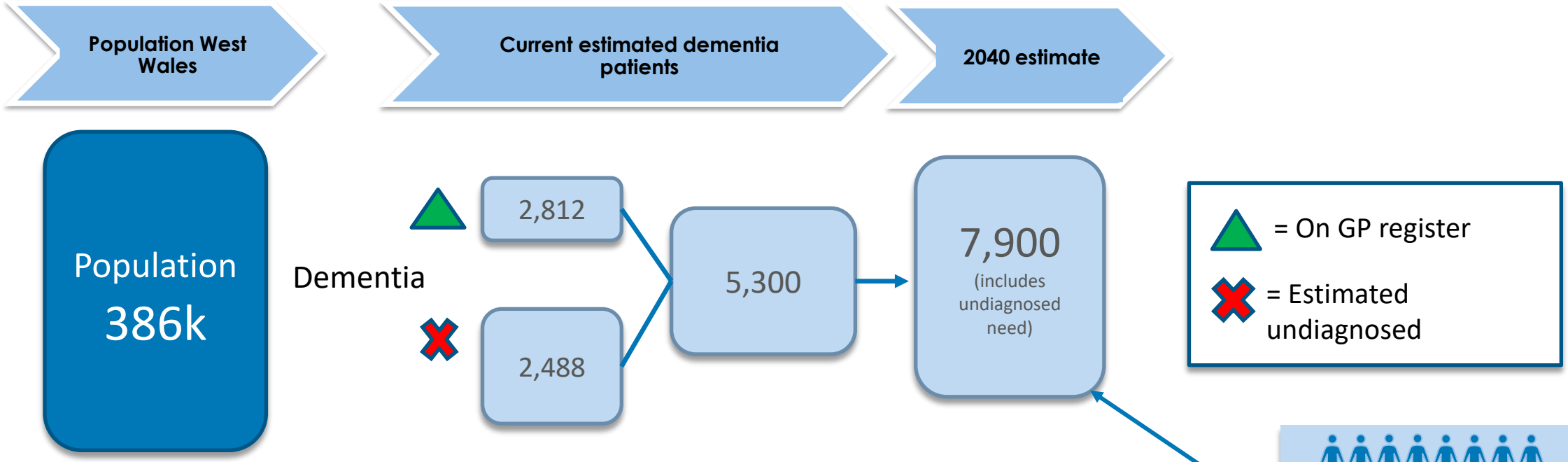
To put this into perspective…

This is equivalent to everyone in Cardigan living with dementia.

*The diagnosis rate is the number of diagnosis compared to the estimated actual prevalence)

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 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*

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) 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 by2040**

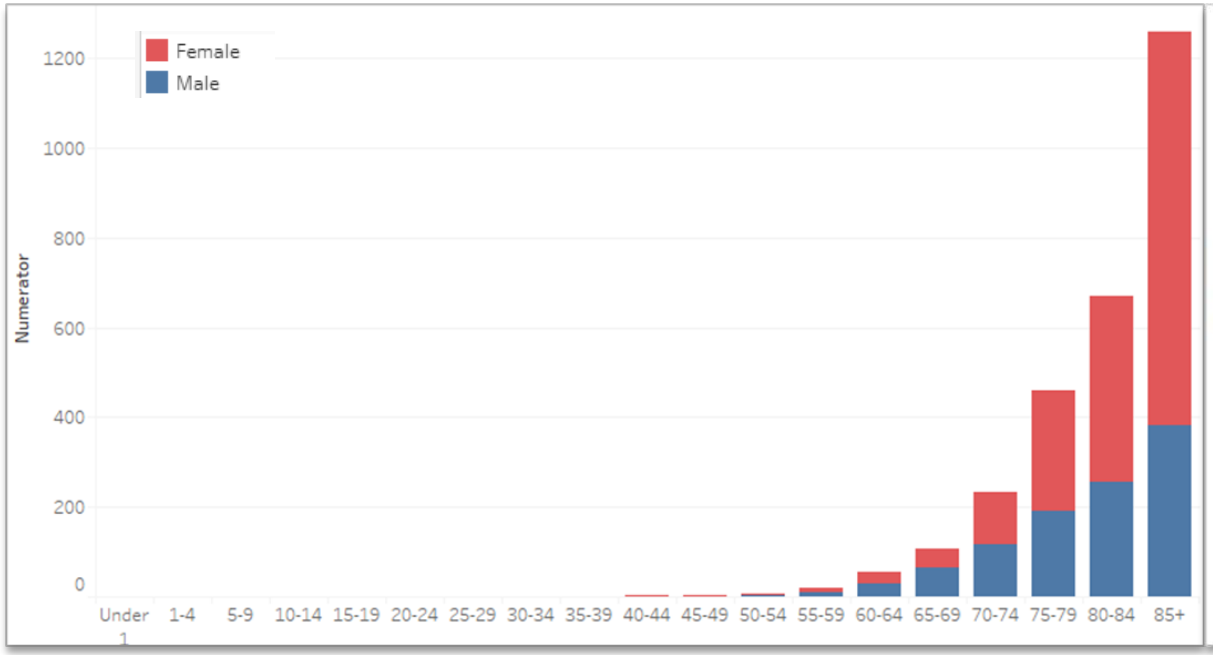
Adult population is reducing across all areas, in particular in **Ceredigion (-11% 2040)**

Decreasing adult population reduces supportive care for the older population

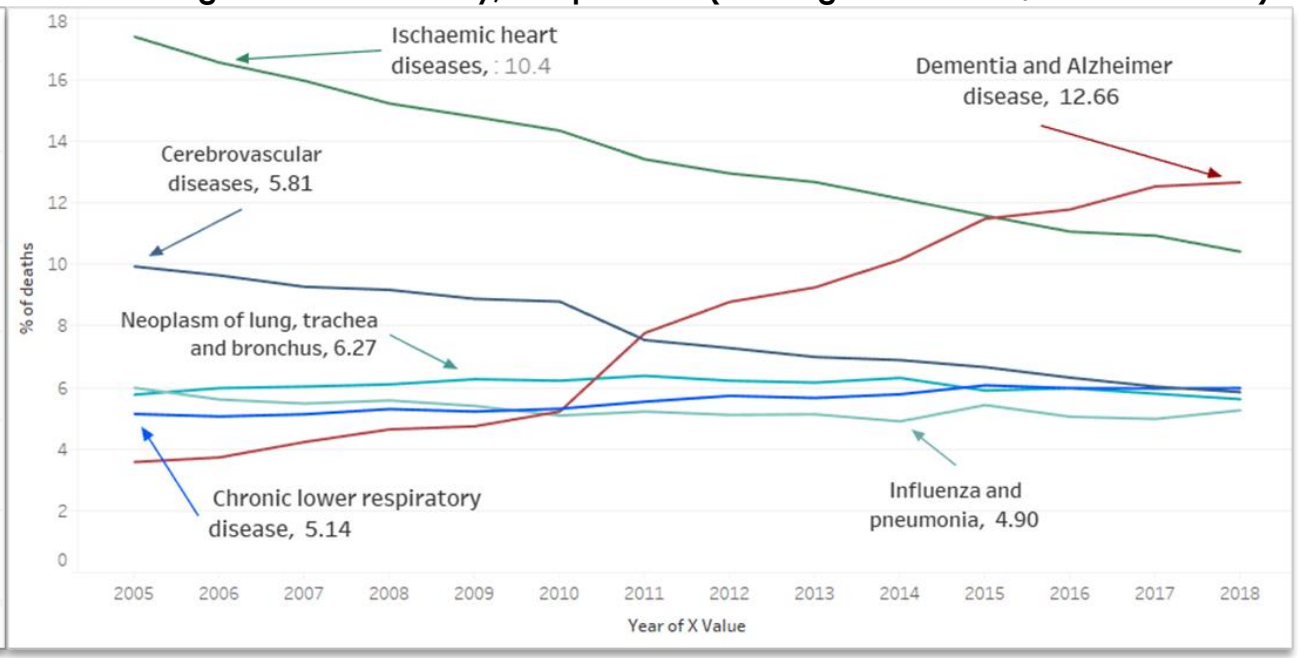
84 patients on the register with young onset dementia (0.06% of adults)

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

Patients on GP registers with a dementia diagnosis West Wales



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



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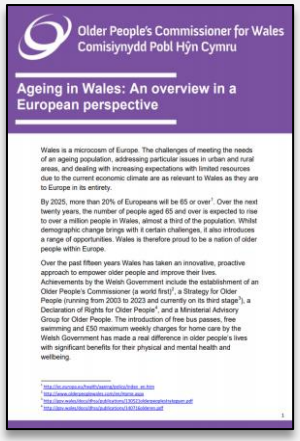
3. Current action plans, regional transformation projects

Relevant dementia documents for Wales:

Any relevant actions will be taken forward in the future palliative & EoLC programme developed as a result of this work & the future strategy

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

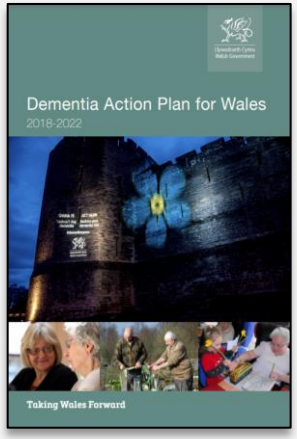
Appropriate accommodation for older people can help to contribute to addressing all of the above

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'

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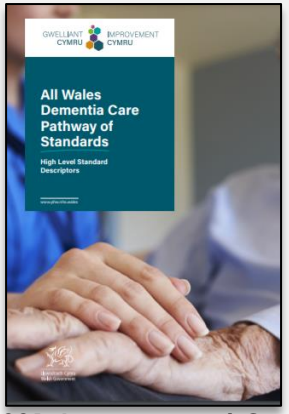
All-Wales Dementia Care Pathway of Standards



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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 it is anticipated that 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 team supports multi-disciplinary teams to meet the care needs of people with dementia in hospital, at home and in care homes. It also aids 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:

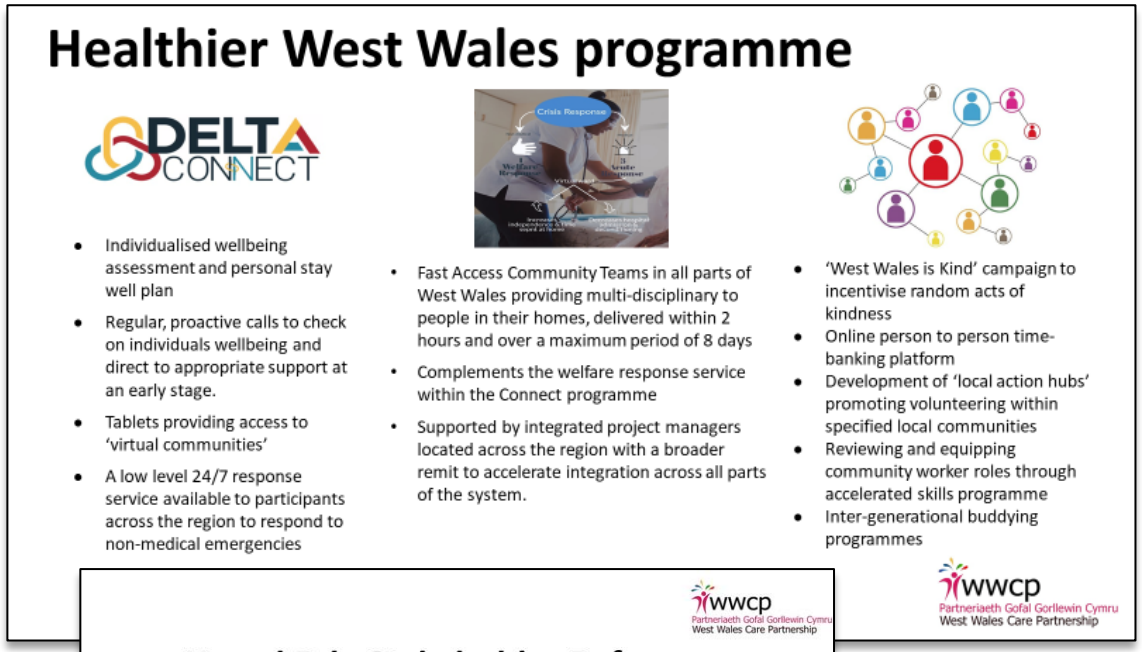
- More work is needed on early detection of those living with dementia and to provide the support required. This will include education for colleagues within primary care to consider when someone with dementia is approaching their end of life and supported to include this group within palliative care registers.
- To 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 3 commitments 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.

Healthier West Wales Transformation Programme 2020

In addition to the ICF dementia programme, there is a West Wales Transformation programme with 3 Transformation programme streams of work -

- Proactive Tec
- Fast-tracked consistent Integration
- Connection for all



The 3 regional transformation programmes were rolled over into 2020/21

- **Programme 1** Delta Connect - A telecare service providing individualised wellbeing assessment & personal stay-well plan. Regular, proactive calls to check on individuals' wellbeing & direction to appropriate support at an early stage. Tablets providing access to 'virtual communities'. A low level 24/7 response service available to participants across the region to respond to non-medical emergencies.
- **Programme 3** Fast Access Community Teams in all parts of West Wales providing multi-disciplinary support to people in their homes, delivered within 2 hours & over a maximum period of 8 days.
- **Programme 7 A 3rd Sector led broad umbrella initiative** – 'West Wales is Kind' campaign to incentivise random acts of kindness. Online person to person time-banking platform.

While it is probable that these programmes will have a beneficial impact on people living with dementia (PLWD) and their carers, there is no mechanism in place to demonstrate this e.g. Project outcomes

4. What does best practice tell us?

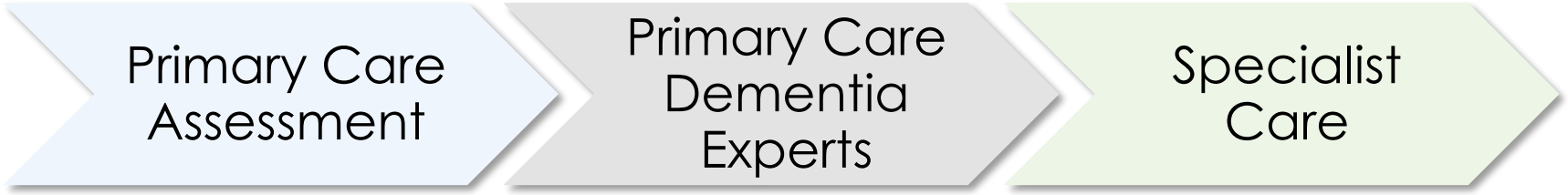
Dementia – key areas of focus

- 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 every bodies business, it is important to understand that there is a need 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 – GPs

- **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**
- GP's, 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 to attend training
- Increase confidence of GPs to improve quality of referrals to specialist services/diagnose dementia
- Support framework for GPs including toolkits, guidelines and regular training
- Rapid access to dementia experts in primary care and specialist memory clinics

Early diagnosis

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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 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

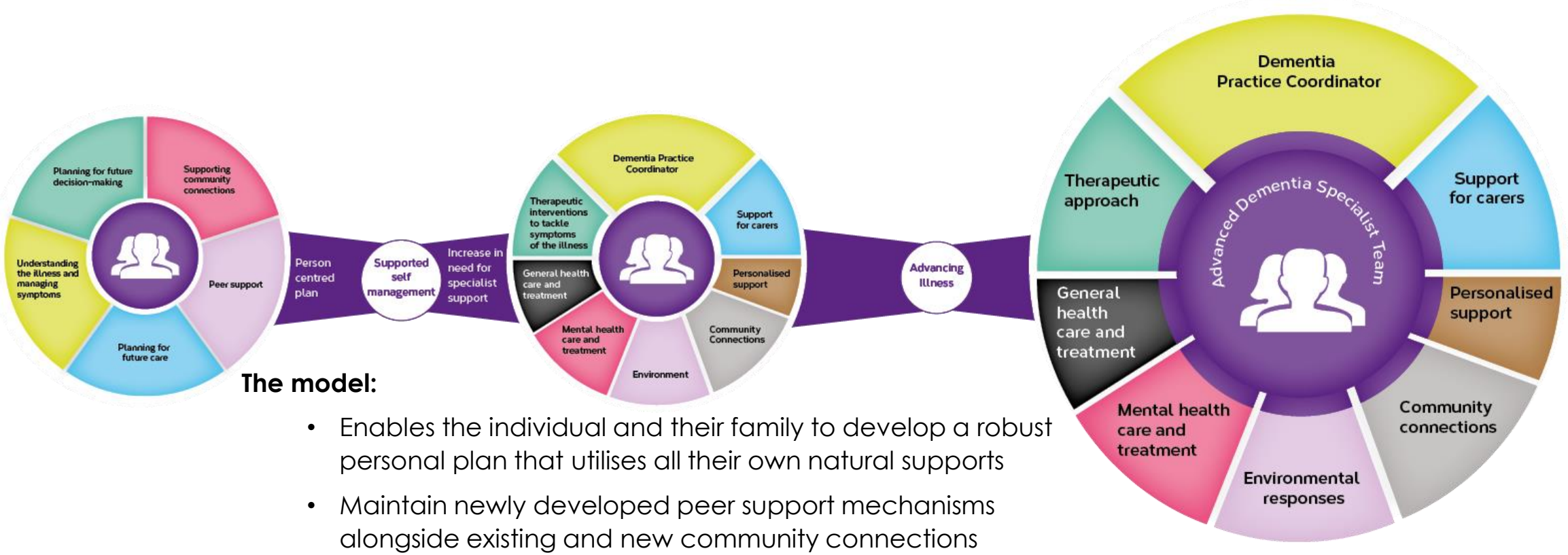
- Services commissioned in line with frameworks
- Memory Services National Accreditation Service MSNAP
- Review of and alignment with best practice from across UK
- Improved brain scan protocols
- Focus on reducing referral to diagnosis times and managing capacity and demand
- Focus also on diagnosis 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 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 all their own natural supports
- Maintain newly developed peer support mechanisms alongside existing and new community connections
- Support each person 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
- Having these 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
- A coordinated approach between all organisations that may 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 high-level strategy has taken place through January to May 2021. It has been led by Attain (an independent provider of health support services) who have been commissioned by Carmarthenshire County Council on behalf of the WWCP to carry out a review of the ICF Dementia Plan along side the development of a high – level dementia strategy vision and service model pathway across the region of Carmarthenshire, Ceredigion and Pembrokeshire. The work has been well supported by stakeholders 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 where possible on the following pages.

Many thanks to those who have 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 Pembs	
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	Pus 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.

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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 overaching 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	Orgs 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 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.

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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	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 - protocol led interventions which will be evaluated	Belief that it can only take place in MAS setting - but some patients can get diagnosed on the wards. There is a need for GPs being skilled to diagnose	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

6. Draft Service vision and model

The following pages contain the draft dementia service vision and model 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 model pathway is very much in draft form and through further engagement with frontline staff, PLWD and their carers we would expect this model to be further developed.

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:

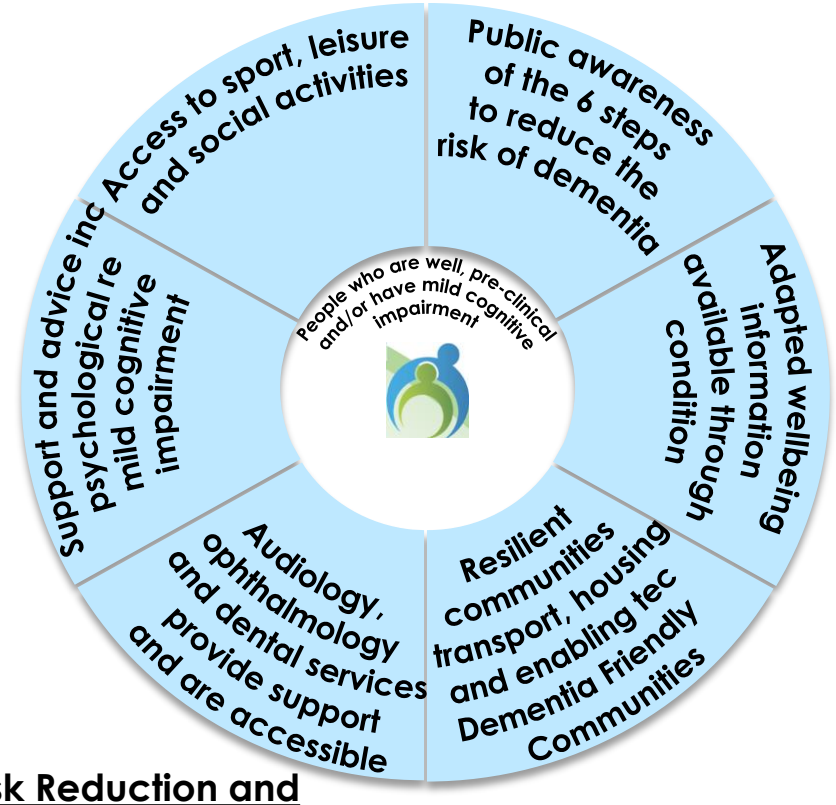
- Clear **regional dementia vision, strategy** and **service model** in line with best practice
- Develop **effective** professional and clinical leadership and **governance** to ensure the service model and **new roles** are designed in line with best practice and **are part of the whole health and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

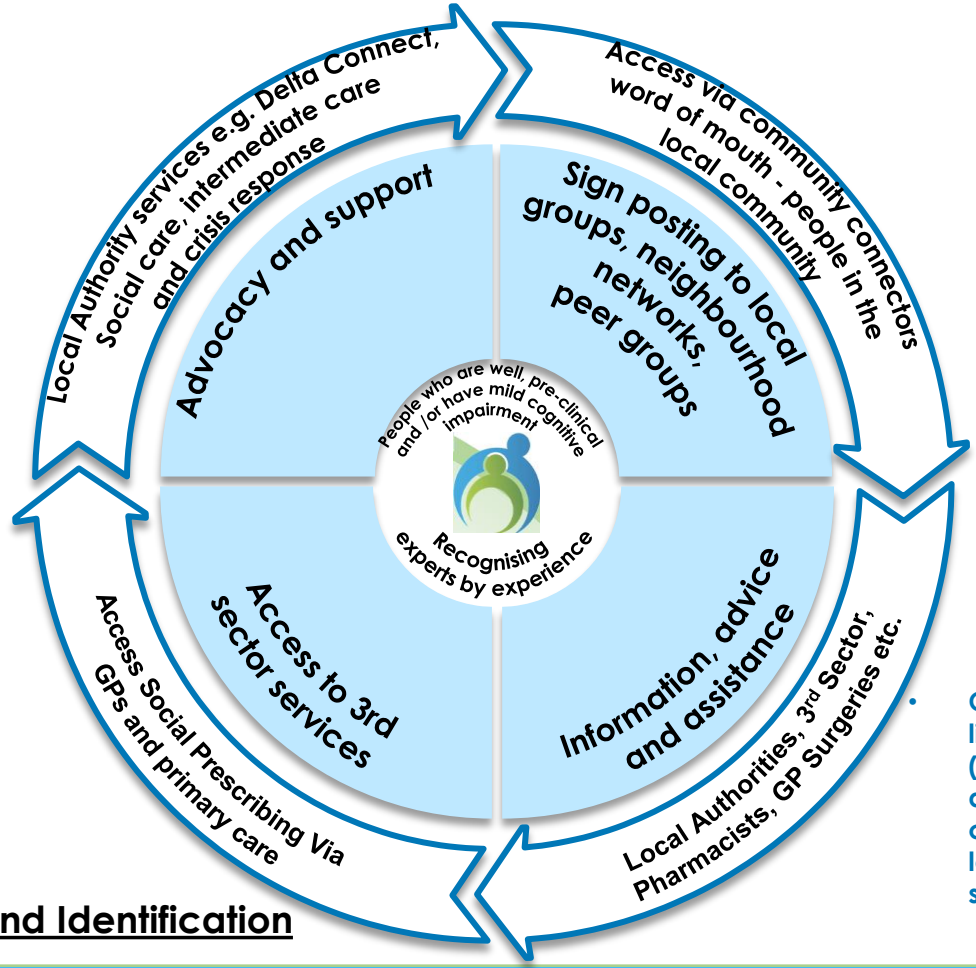
- **Joint commissioning** for **integrated care,** ensuring **equity** of **access** and **provision across West Wales**
- **Optimise the use of estate** - build on localities and **provide support closer to home** e.g. local meeting places/hubs where people can connect
- **Adapting IT** so that it reflects 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 care co-ordinators/case managers**
- **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 draft dementia wellbeing pathway

Working with partners across West Wales we will develop our model together focusing on **streamlining pathways and placing the PLWD and their carers at the centre of our service provision.** We will **implement strategies** to **achieve early diagnosis, supporting GPs and staff in primary care wherever possible** to diagnose **and improve quality of referrals to specialist services**. We will focus on **implementing best practice within social care, care homes, domiciliary care and specialist services**. Implementation of **care pathways**, particularly post diagnostic support, will **include 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 amongst different care providers to ensure they understand the end-of-life care plan.**





Carers and people living with dementia (PLWD) need clear and accessible information connecting them to local peer groups for support at the outset.

Wellbeing, Risk Reduction and Delaying Onset, Raising Awareness and Understanding

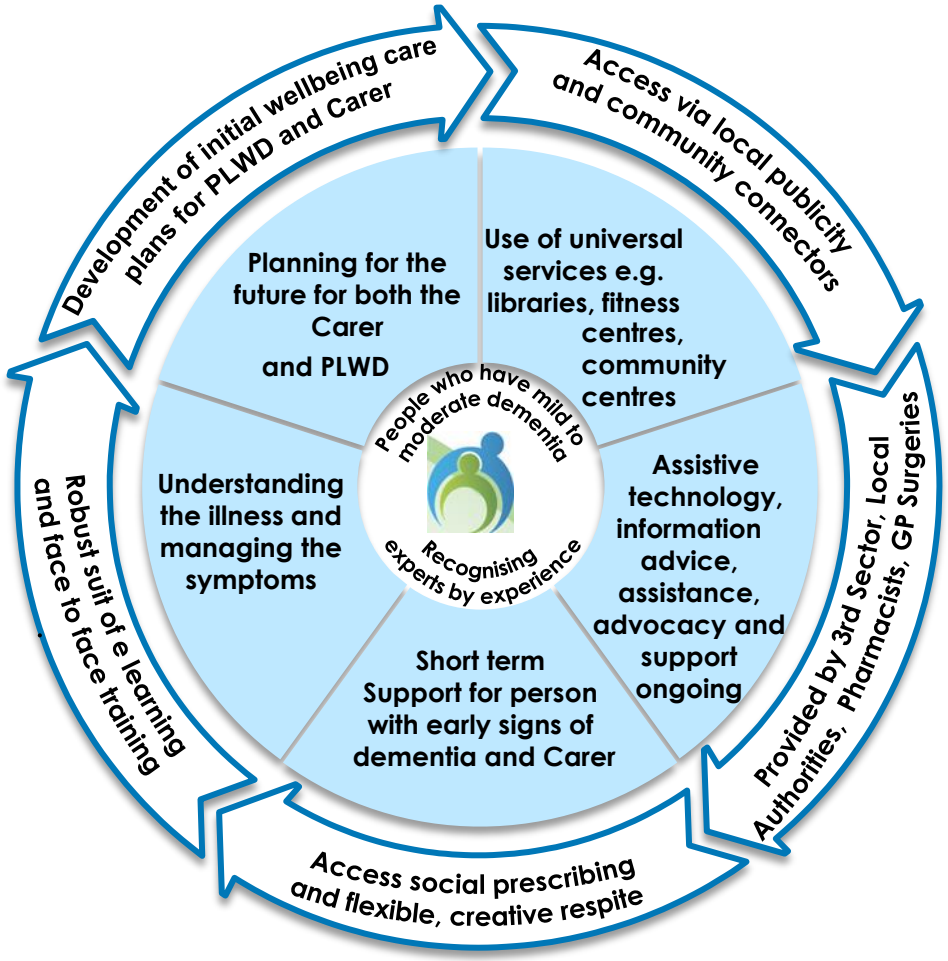
Recognition and Identification

Underpinned by access to assistive technology, training - Implementation of the Recognition and Good Work Frameworks

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

Assessment and diagnosis

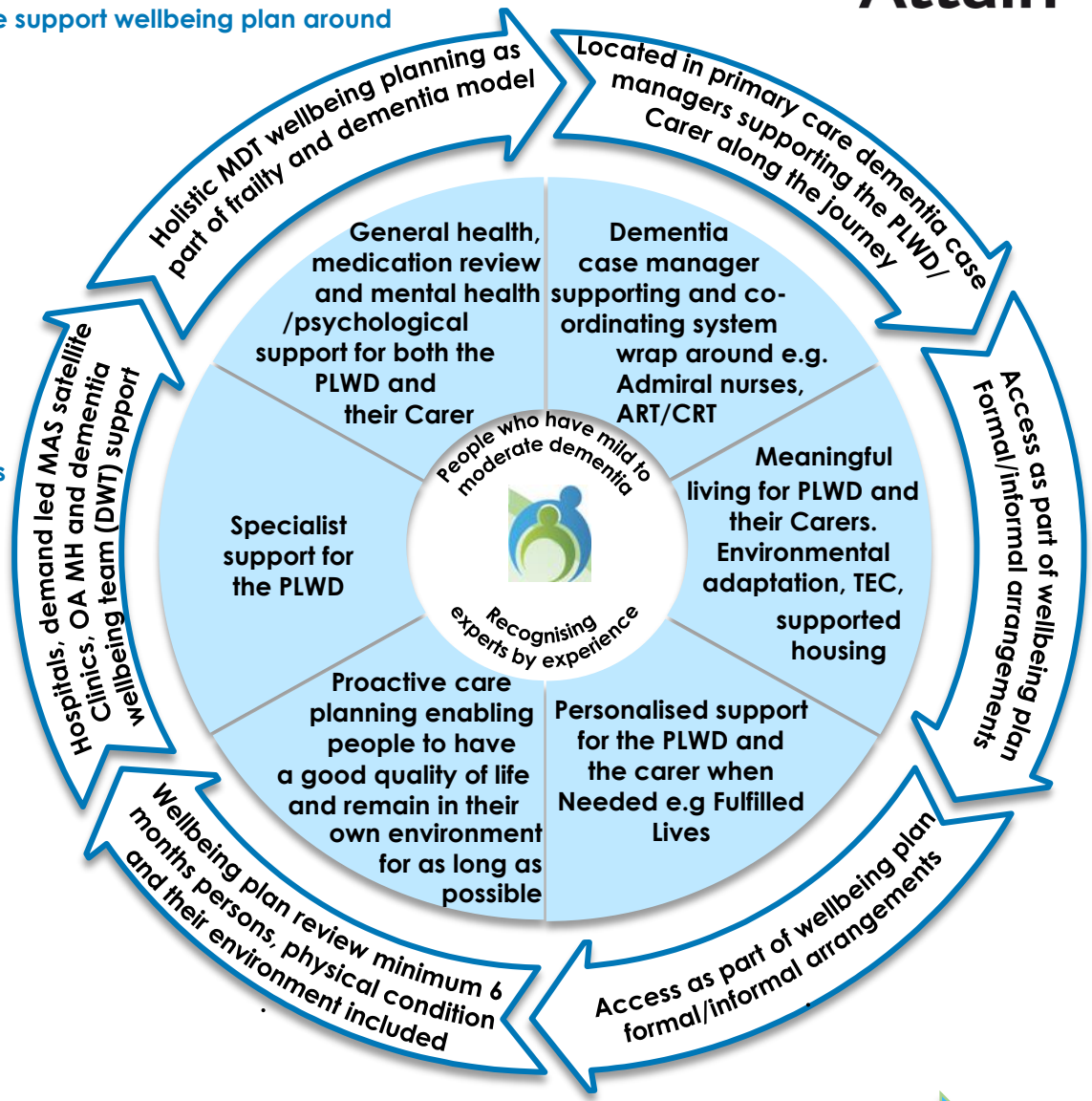
- Enabling generic services (e.g. social work, domiciliary care, care homes, district nursing, OT, physio etc.) to support people with dementia - education - what signs to look for and what to expect
- Widening those who can diagnose – training and advice from the Dementia Wellbeing Team (DWT)



Living well with dementia

Holistic MDT = providing stable support wellbeing plan around the person including:

- Social care,
- OT
- Key workers/ assistive technology lead,
- Admiral nurse.
- Primary care,
- 3rd sector,
- Older Adult mental health
- Adult MH for young onset
- Advice and training as required from DWT
- Secondary care consultants



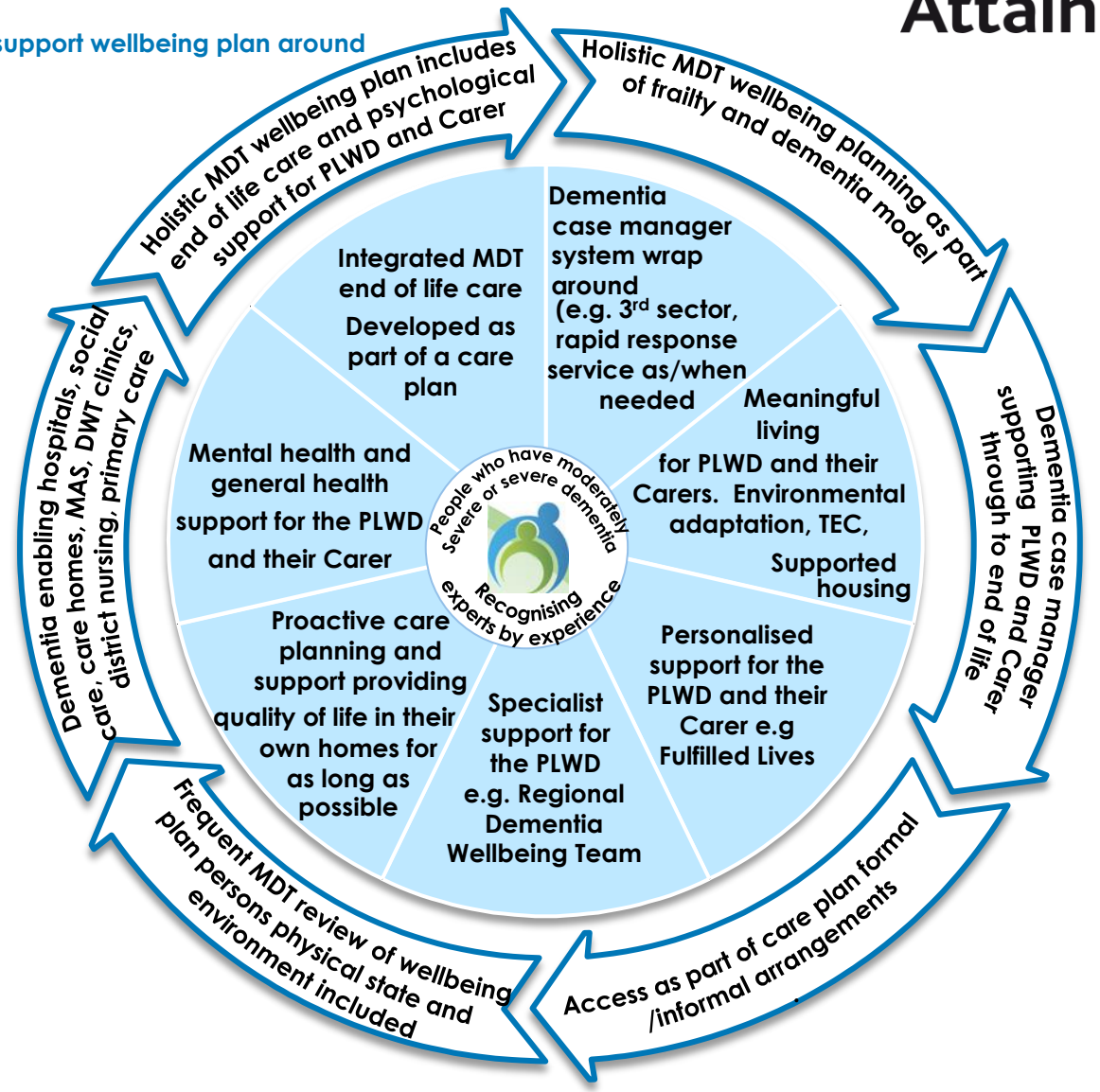
Under pinned by access to assistive technology, training - Implementation of the Recognition and Good Work Frameworks

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

The need for increased support

Holistic MDT = providing stable support wellbeing plan around the person including:

- Social care,
- OT
- Key workers/ assistive technology lead,
- Admiral nurse.
- Primary care,
- 3rd sector,
- Older Adult mental health
- Adult MH for young onset
- Advice and training as required from DWT
- Secondary care consultants

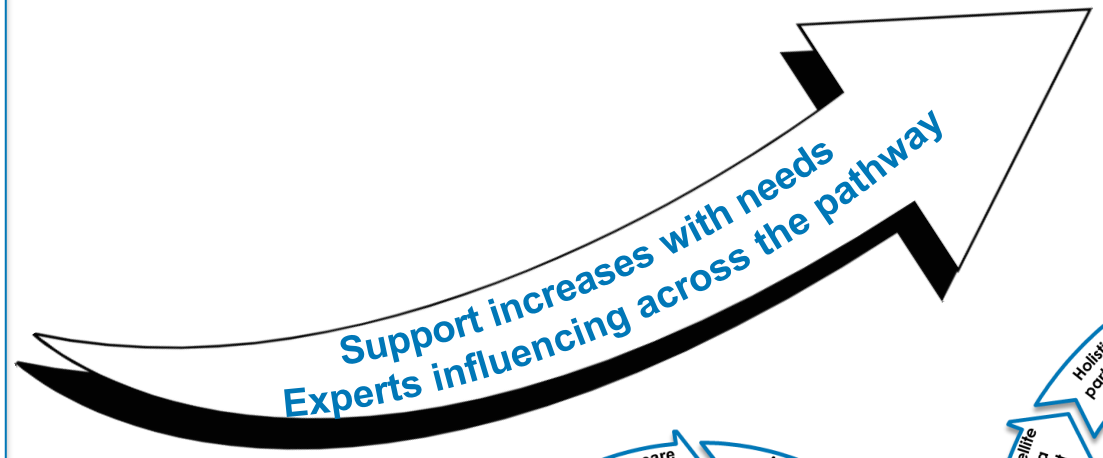


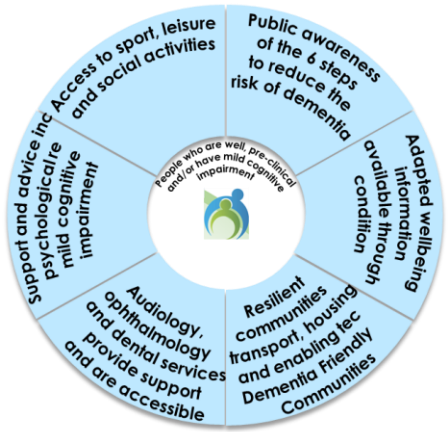
- **Implementation of the Good Work Framework -** we need to consider the learning and development needs of everyone who is affected in some way by dementia. This includes people living with dementia, carers, frontline staff, managers, commissioners, regulators, researchers, shopkeepers, next door neighbours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

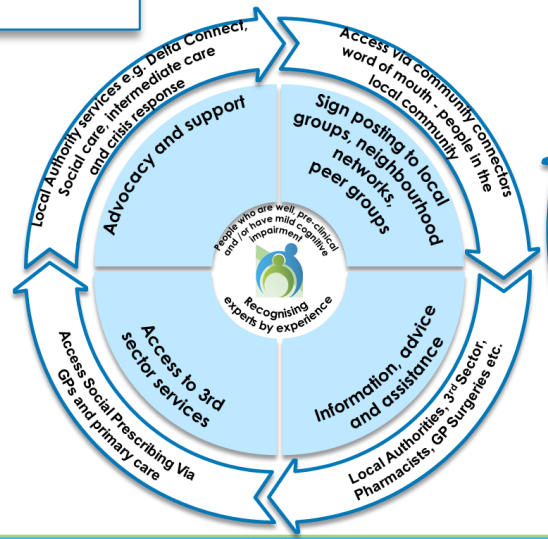
Under pinned by access to assistive technology, training - Implementation of the Recognition and Good Work Frameworks

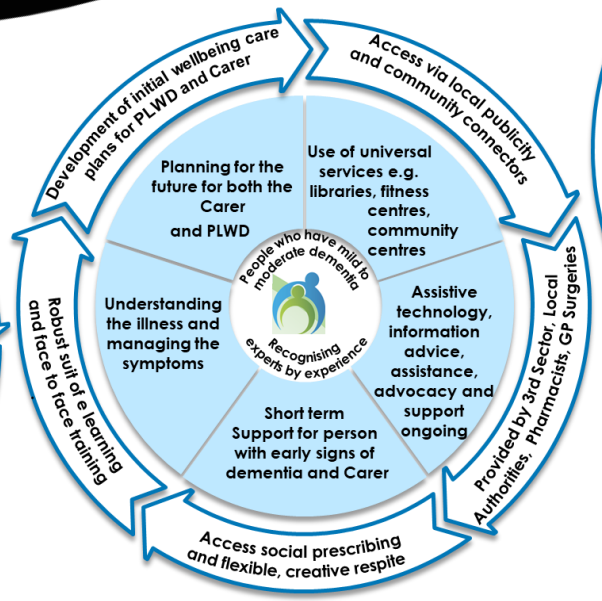
What good looks like for West Wales – The draft dementia wellbeing pathway

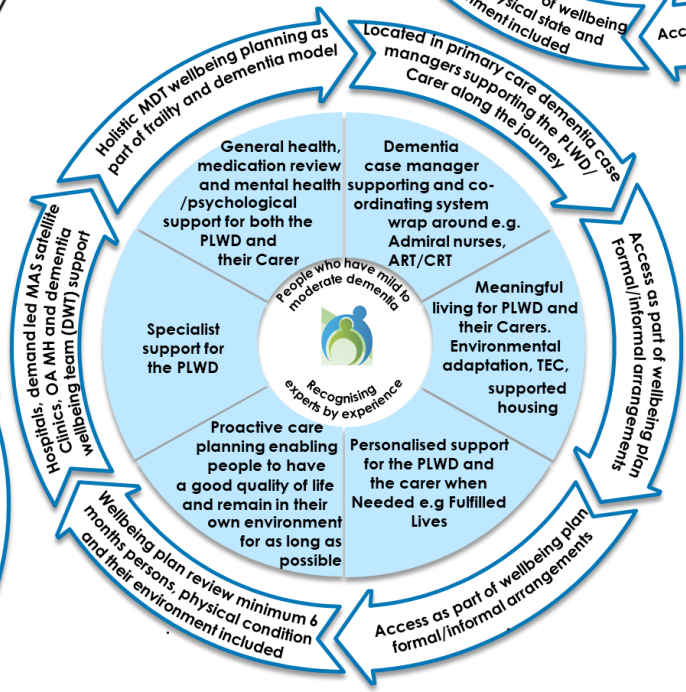
- This draft model, illustrates a new more joined up way of providing services. It is based on best practice and existing services within West Wales. The model requires further co-design with frontline staff, PLWD and their carers
- The service model should be underpinned with an agreed set of service delivery principles which need to be to be developed

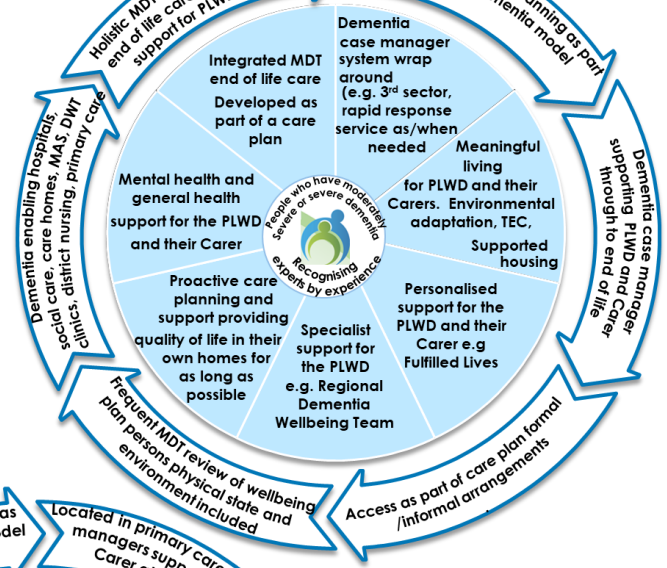












Under pinned by access to assistive technology, training - Implementation of the Recognition and Good Work Frameworks

7. Taking the work forward through co-design and a programme approach

Alongside this work and in order to align funding with the new service model pathway, Attain were asked to carry out a review of the regional ICF dementia projects and to provide a steer as to what services should continue to be funded as well as provide an indication on any additional initiatives that should be undertaken during 2021/22. At the point of writing this strategy future Government Funding for Dementia is not fully known. The following slide contains a summary of project initiatives for 2021/22 which will continue to be funded while the draft dementia service vision, model and strategy are fully developed. For more detail please see appendix 2.

ICF Dementia Programme Initiatives for 2021/22

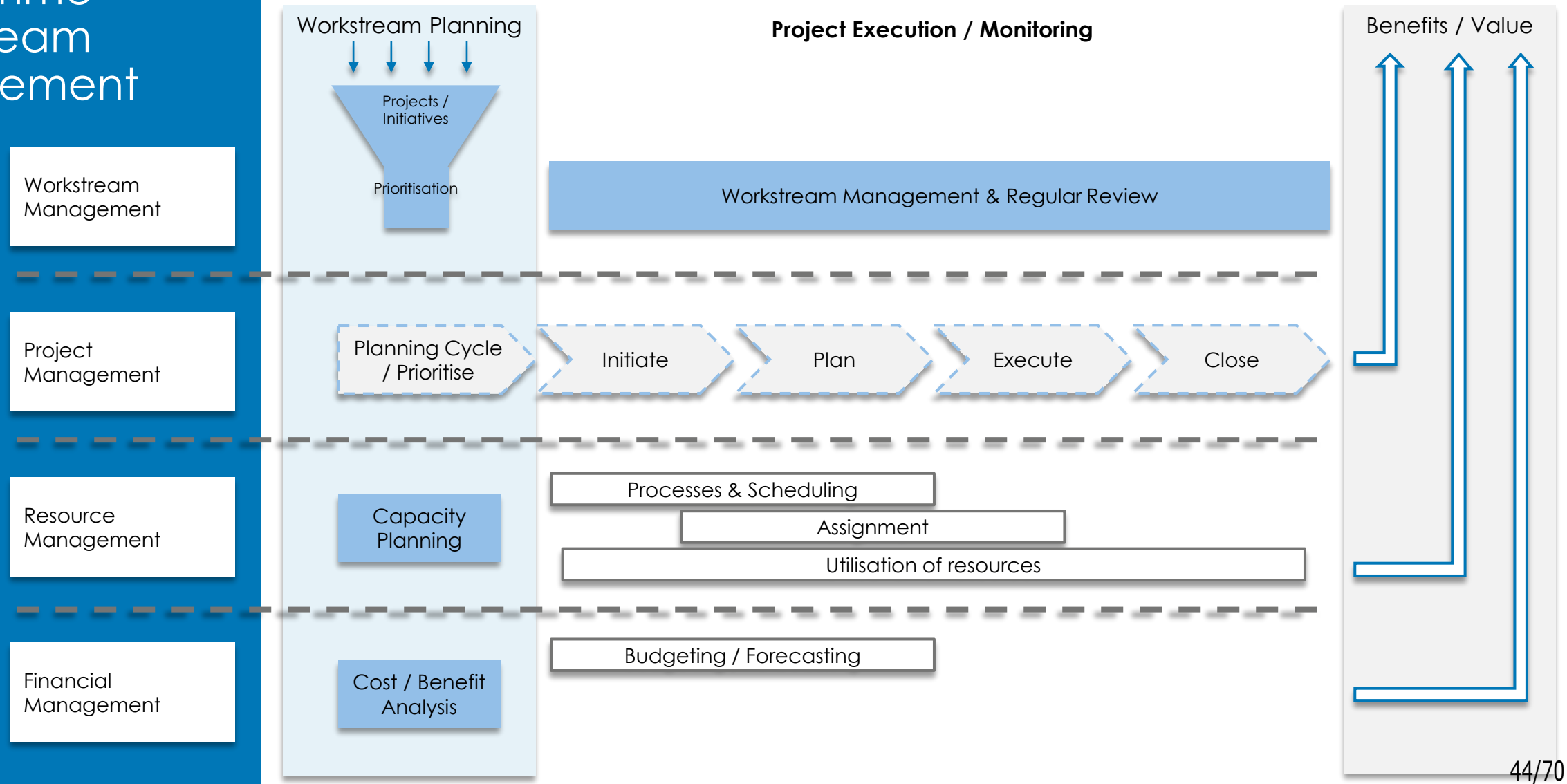
Ref	Project Title	Project description	In line with best practice	All Wales Dementia Action Plan	Welsh Dementia Standards	Rationale to continue funding during 2021/22
REG DEM 2a	Increase the number of Advanced Scope Practitioners	Part of the memory assessment service nurse practitioners able to diagnose and able to prescribe – 3 - one for each county. Procured soft wear to improve diagnosis.	✓	✓	✓	Unclear as to what the outcomes have been in relation to these staff what has consistently been delivered? Continue with pilot during 2021/21 providing there are metrics and outcome in place that are reported quarterly to the WWCP Dementia Steering Group
REG DEM 2b	Extend the application of technology	No allocation for this year	✓	✓	The standards focus on digital platforms on which to assess or meet with people with dementia and their carers	**There was no allocation to technology during 2020/21 – provision needs to be found as technology is central to supporting those PLWD and their carers**
REG DEM 2c	Establish skilled dementia advice and support	Admiral nurses 7 funded through this band 6 OA MH service funds a band 7 nurse who oversees	✓	✓	✓	
REG DEM 2d	Develop current investment in Dementia Support Workers - remodel	Remodel of the navigator, case co-ordinator role –	✓	✓	✓	To achieve equity of access and provision consider seed funding pilots of Fulfilled Lives in Ceredigion and Pembs and provide robust outcomes of pilots
REG DEM 2e	Extend the role of Community Connectors	Ambition was for a community connector for every county	✓	✓	✓	Continue with the community connector role in Pembs – Role to provide evidence of effectiveness reporting to the Regional Dementia Steering group. **Carry out a mapping exercise which includes a descriptor of what each role does across the region. The role of the dementia case manager needs to be agreed as part of the new regional dementia model of care**
REG DEM 2h	Rapid response to care breakdown	Emergency to support - top up funding for councils who may have come to an end of their respite.	✓	✓	✓	Access to appropriate respite has been raised as an issue during the regional stakeholder discussion. During 2021/22 utilise this funding to review access to respite care for those with dementia and their carers – consider different approaches to providing respite to meet the needs of those with dementia and their carers to align with best practice and the new model of care
REG DEM 3a	Regional wellbeing team.	Specialist support to reduce distress presenting as behaviour that challenges	✓	✓	✓	Launch services and report on outcome's and impact of the service during 2021/22 to provide evidence for future funding

Delivering the initiatives through programme management

In additional to developing the vision, service model pathway, strategy and reviewing the ICP dementia project initiatives, 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 please 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



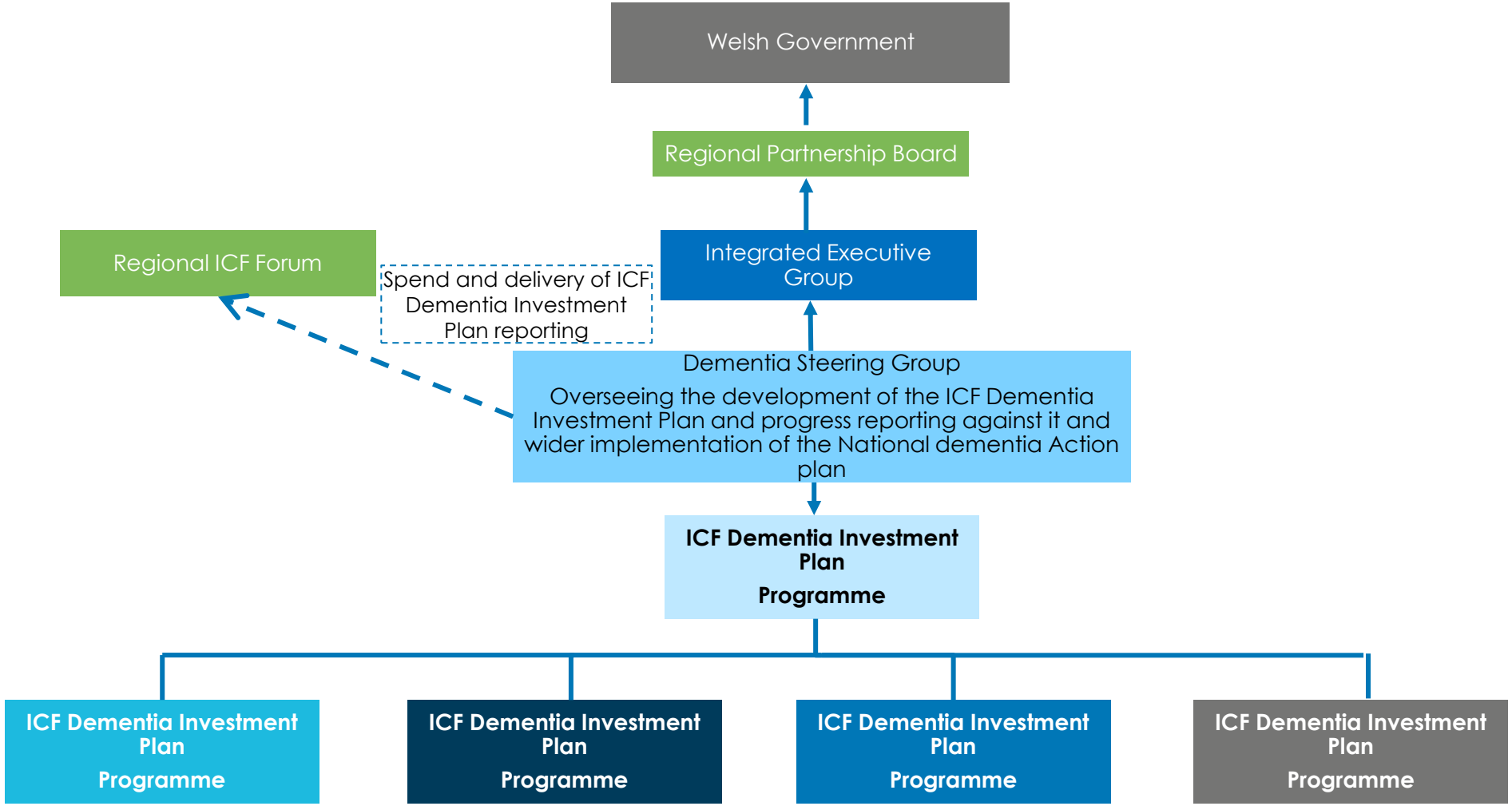
Proposed Delivery Approach: Workstream Management

Below is an indicative set of ICF Dementia Workstreams for 2021/21. Each workstream should be led by a senior leader within the system. Given all services are front line, resources will need to be idenfied to manage the programme and resources will be required over the life of the programme to enable continuation of service delivery while staff work to design and develop the services.

	Governance, Strategy Dev and Programme Management PMO	Workstream 1:	Workstream 2:	Workstream 3:
Aim	To develop a strategy and the 'at scale' operating model. Implement strategic leadership. Oversight of performance to drive consistency in decision making and improved care	Enabling the change and improving prevention	Improving diagnosis, early management and wraparound community services - Service delivery	Complex presentation & end of life care
Programmes	• Dementia strategy, vision and service model • WWCP programme governance structure • ICF Demetria programme performance dashboard • Oversight of 2021/22 projects and allocation for 2022 onwards • Enable data intelligence to support decision making & planning	• Develop an integrated, structured approach to skills development • Develop a Dementia Roadmap	• Increase the number of Advanced Scope Practitioners • Extend the application of technology • Establish skilled dementia advice and support – Admiral nurses • Continue to pilot Fulfilled Lives and Virtual Day service and provide robust evidence for rolling out the services across the region if appropriate • Map navigator, social prescribing and community connector type roles develop the business case for dementia case co-ordinator role • Continue with the community connector role in Pembs and share activity and outcomes as part of reporting • Respite - During 2021/22 utilise this funding to review access to respite care for those with dementia and their carers – consider different approaches to providing respite to meet the needs of those with dementia and their carers to align with best practice and the new model of care	• Regional Wellbeing Team - Specialist support to reduce distress presenting as behaviour that challenges

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

Proposed Integrated Care Fund (ICF) Dementia Programme Governance Arrangements



8. Next steps for 2021/22

Next steps

Delivering the programme:

- Agree the rationale to continue funding during 2021/22 as outlined in section 7 of the high-level strategy
- Identify resource to set up and manage the programme of work across partners
- 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

Developing the strategy:

- Further co-design of the draft vision and service model pathway with frontline staff, PLWD and their carers through a series of workshops, surveys and focus groups
- Finalise the vision and service model pathway and socialise them so all partners are aware of the direction of travel for dementia services within West Wales
- Update the programme plan with the new service developments required to deliver the vision and service model 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

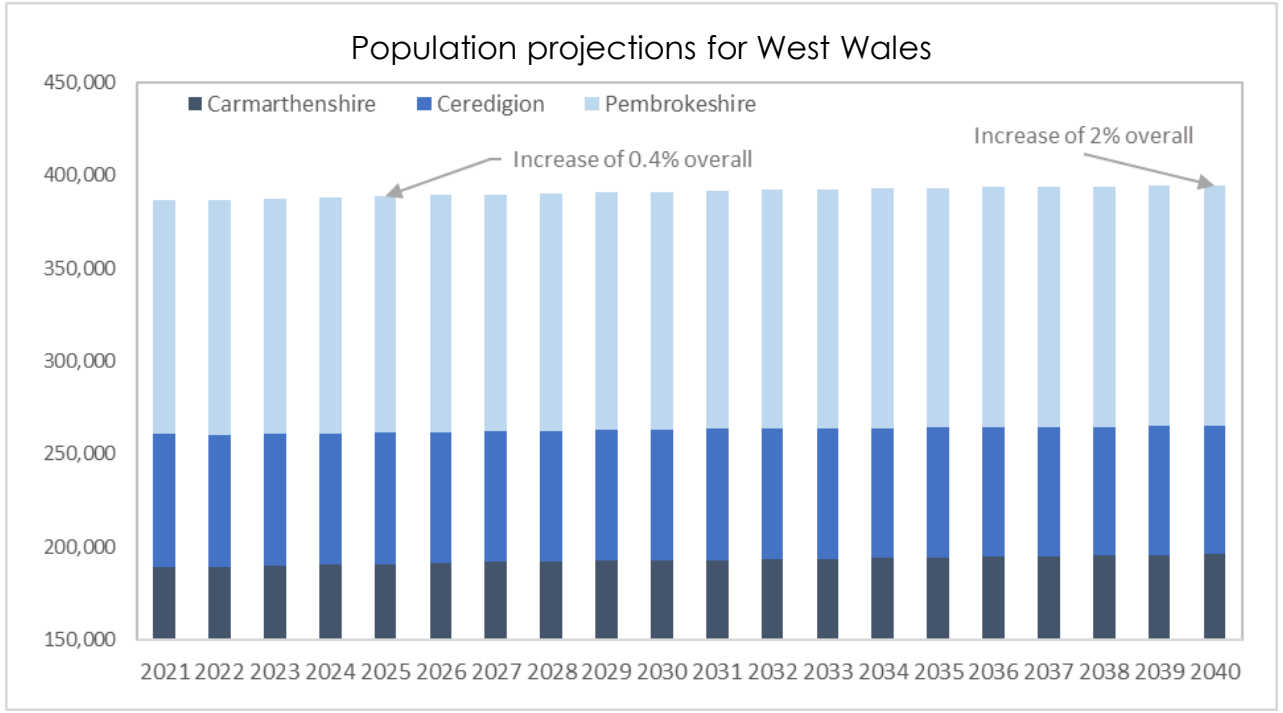
9. Appendix 1: West Wales Population Analysis

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

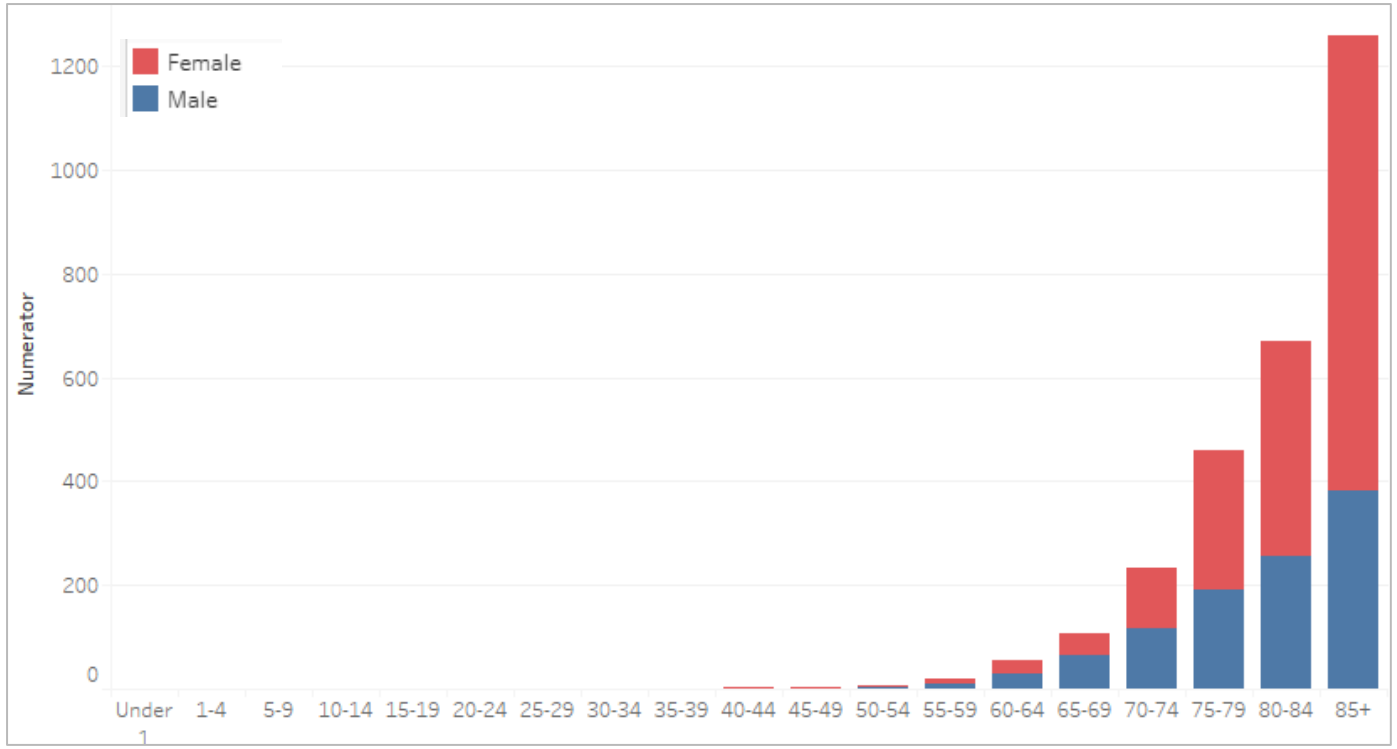
Nearly 50% of the female dementia patients are over 85 years old compared to 36% of the male patients. This means that 45% of the total dementia patients over the age of 85 years old. This age group is set to grow substantially over the next 20 years, and is due to make up over 10% of the West Wales 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

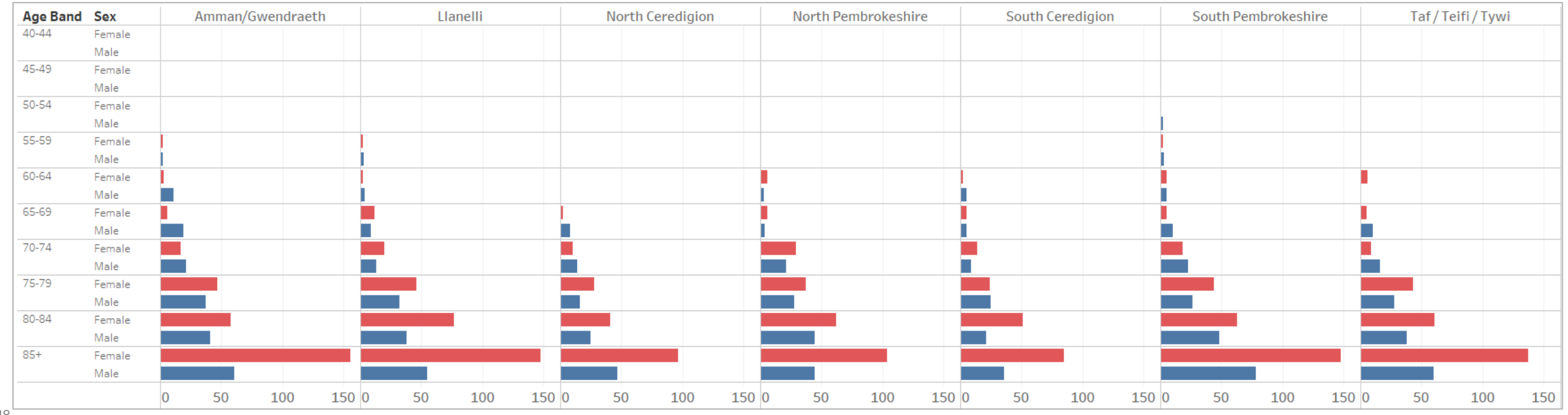
Dementia by cluster

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

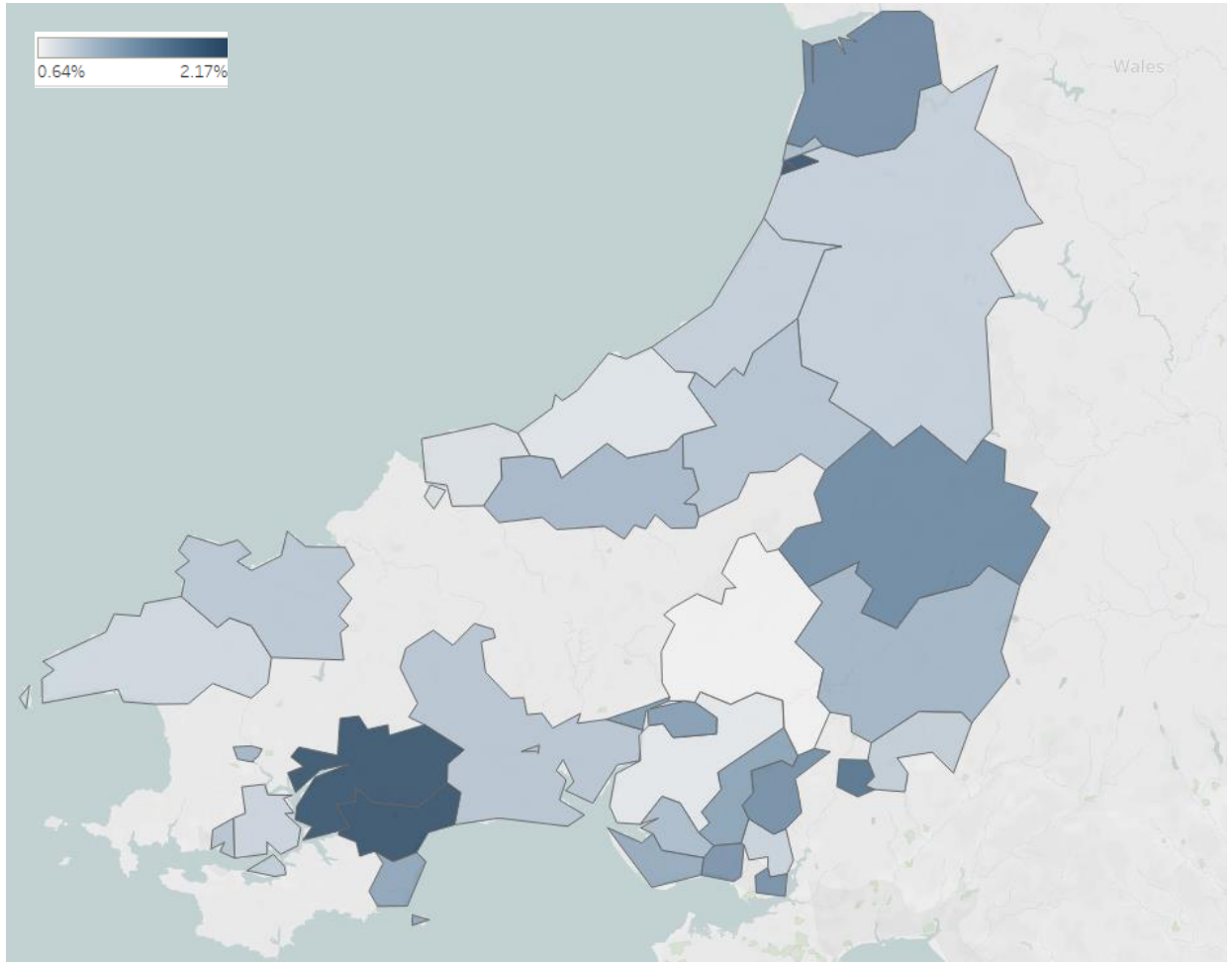


Source: GP QOF and GNS

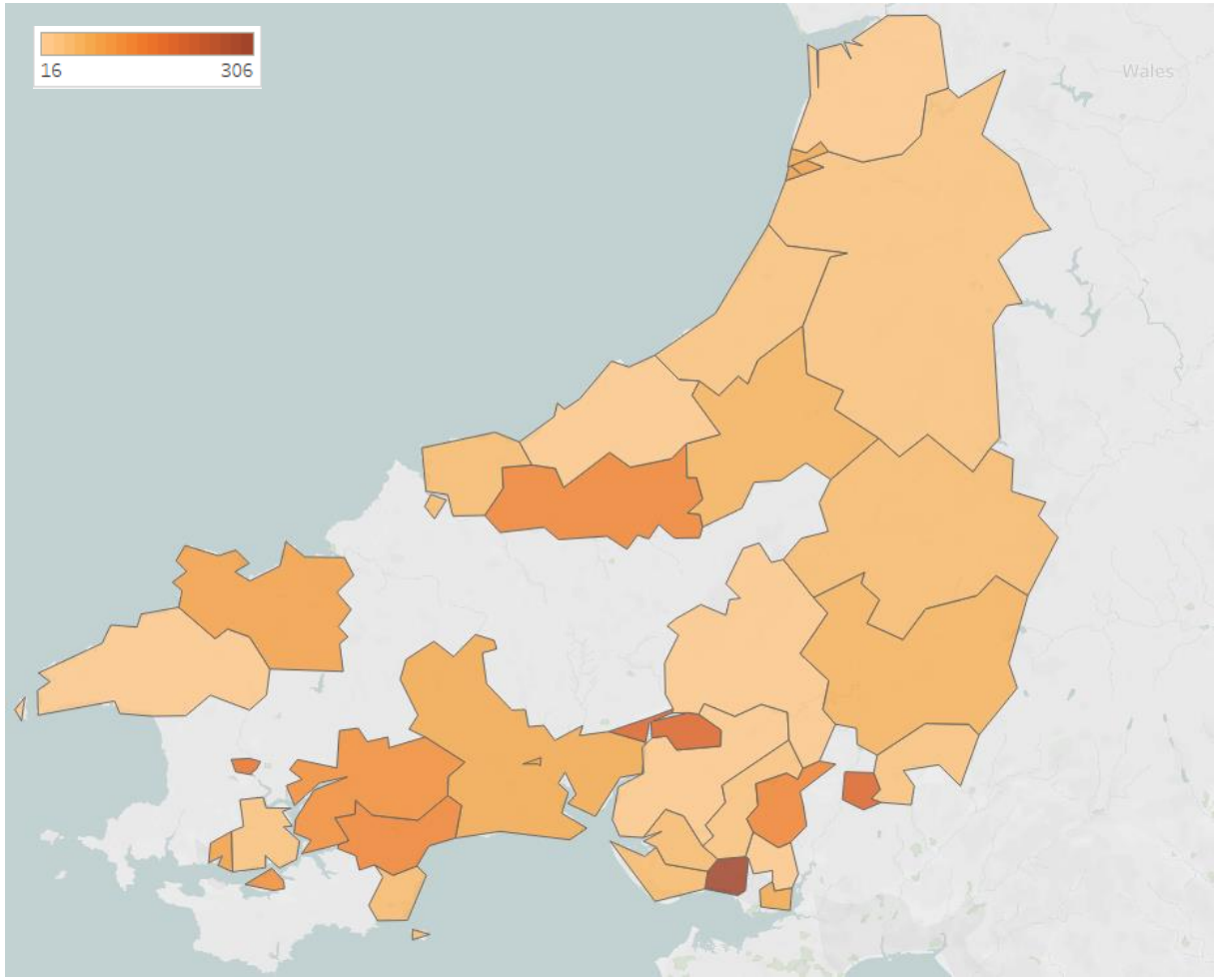
Map

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



Health board comparison

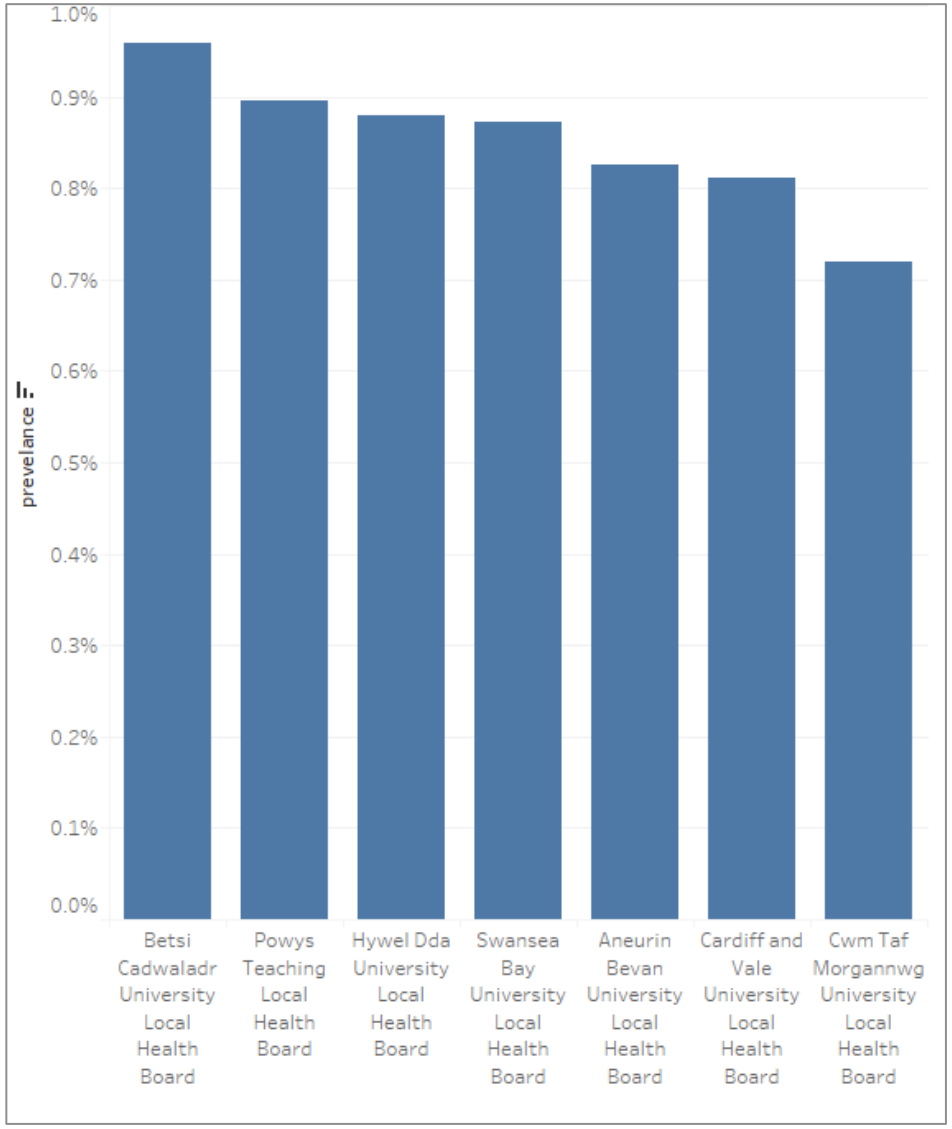
The graph to the right shows the prevalence rates for dementia recorded in the GP registers (according to QOF definitions). Note, this is likely to be a lower than actual perveance rate due to using GP registered population from the GP system as the denominator (and not resident population, it also includes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

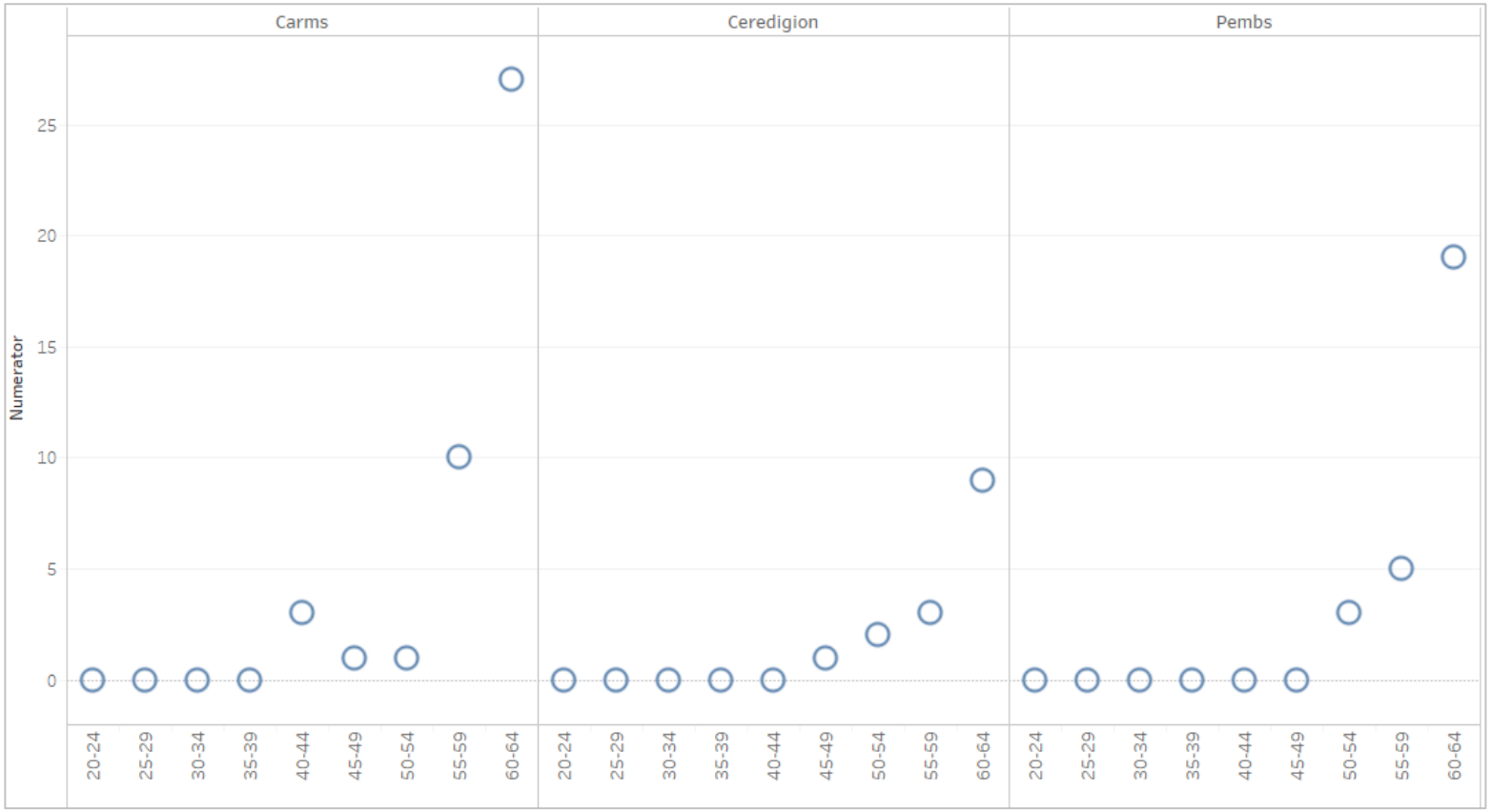


Young onset

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: WWCP ICF Dementia Programme Review

Project Requirement	Progress	Key Accomplishment
Review the current ICF Plan in anticipation of the overarching strategy and delivery plan.	✓	• A review has been carried out with the Regional Programme Lead. This report has been developed following the review

Workstream 1: Enabling the change and improving prevention

Ref	Project Title	Project description	Project success	In line with best practice	In line with the All Wales Dementia Action Plan	In line with Welsh Dementia Standards	Issues to consider	Rationale to continue funding during 2021/22
REG DEM 1b	Develop an integrated, structured approach to skills development	Due to COVID training it was not possible to - Karen is the OT lead for Neil's team she has done some specific training on dealings which will be shared across OT's	Funding has been spent on training for the OT within the wellbeing team	✓	✓	✓	This has not been achieved due to C-19. Funding for 2020/21 was utilised through training the lead t in the wellbeing team with the aim of sharing the learning with OT's across West Wales – this needs to be monitored and the outcome reported on. There is no evidence of developing an integrated approach in relation to this funding stream. An integrated approach to delivering services needs to be a priority	During 2021/22 – A clear training framework for staff and carers needs to be drafted to meet the need of the new service model
REG DEM P1	Develop a Dementia Roadmap	List of services that would be useful to you - can't create that until we get those service in place. One off	The roadmap will be useful once the model of care has been developed	✓	✓	✓	Accessing support at the right time is best practice and inline with the Welsh dementia standards. The roadmap will enable carers and people with dementia to access services at the right time and will help them to understand what service are available and at what stage of their dementia journey The roadmap should be developed once the dementia strategy and model of care for West Wales has been finalised	Develop a roadmap of services for people wit dementia and their carers to utilise to aid navigation through out their journey

KEY: Project Success RAG rating: **GREEN – Project Implemented AMBER – Project Partially Implemented Red – Project Not implemented.** Funding Rationale: **GREEN – Continue RED - Discontinue**

Workstream 2: Improving diagnosis, early management and wraparound community services - Service delivery (1)

Ref	Project Title	Project description	Project success	In line with best practice	In line with the All Wales Dementia Action Plan	In line with All Wales Dementia Standards	Issues to consider	Rationale to continue funding during 2021/22
REG DEM 2a	Increase the number of Advanced Scope Practitioners	Part of the memory assessment service nurse practitioners able to diagnose and able to prescribe – 3 - one for each county. Procured soft wear for them to improve diagnosis.	Staff in place and have consistently delivered	✓	✓	✓	Purchased 21 'medical devices', with training and a license for 3 years to use iPads situated in Primary Care (01/20 minutes test) where people are concerned about their memories. Red Amber Green instant results, refer to Memory Assessment Service via GP, GP watchful waiting, no issue respectively.	Unclear as to what the outcomes have been in relation to these staff what has consistently been delivered? Continue with pilot during 2021/21 providing there are metrics and outcome in place that are reported quarterly to the WWCP Dementia Steering Group
REG DEM 2b	Extend the application of technology	No allocation for this year	See issues column	**The use of technology to support those with dementia and their carers is central to any best practice service model**	✓	The standards make no reference to the use of technology for people with dementia and their carers. The standards focus on digital platforms on which to assess or meet with people with dementia and their carers	Delta connect staff have been trained by the wellbeing team to be able to better support those with dementia and their carers they have also been trained to use the medical devices in the above project – **there is a need to understand the impact of this. There is also a need to fully understand what assistive technology is offered across each of the counties**	**There was no allocation to technology during 2020/21 – provision needs to be found**
REG DEM 2c	Establish skilled dementia advice and support	Admiral nurses 7 funded through this band 6 OA MH service funds a band 7 nurse who oversees	Not all are in post	✓	✓	✓	Next year 90k match funding Dementia UK - working in an MT way linked to locality teams.	
REG DEM 2d	Develop current investment in Dementia Support Workers and remodel	Remodel of the navigator, case co-ordinator role –	The project has not been implemented	✓	✓	✓	Due to the lack of a regional dementia service model this project has never been implemented - once agreed there will be a need to remodel **N.B Slippage has funded the fulfilled lives project in Carms in addition to a virtual day service pilot both of which are aligned to good practice**	To achieve equity of access and provision consider seed funding pilots of Fulfilled Lives in Ceredigion and Pembs and provide robust outcomes of pilots

KEY: Project Success RAG rating: **GREEN – Project Implemented AMBER – Project Partially Implemented Red – Project Not implemented.** Funding Rationale: **GREEN – Continue RED - Discontinue**

Workstream 2: Improving diagnosis, early management and wraparound community services- Service delivery (2)

Ref	Project Title	Project description	Project success	In line with best practice	In line with the All Wales Dementia Action Plan	In line with Welsh Dementia Standards	Issues to consider	Rationale to continue funding during 2021/22
REG DEM 2e	Extend the role of Community Connectors	Ambition was for a community connector for every county	This project has not been fully implemented – with a 6 month pilot in place	✓	✓	✓	Currently there is a 6 month placement in Pembs. Community connector, navigator, social prescribing type roles have not been mapped effectively, these roles need to be mapped before any decision can be made as to whether this community connector role is required. Community navigators, social prescribers and community connector type roles need to be defined. There is a question as to whether would fulfilled lives would deliver more?	Continue with the community connector role in Pembs – Role to provide evidence of effectiveness reporting to the Regional Dementia Steering group. **Carry out a mapping exercise which includes a descriptor of what each role does across the region. The role of the dementia care co-ordinator needs to be agreed as part of the new regional dementia model of care**
REG DEM 2h	Rapid response to care breakdown	Emergency to support - top up funding for councils who may have come to an end of their respite.	Fully implemented	✓	✓	✓	Further clarity is required to confirm if this initiative should continue. The All Wales Dementia Action Plan requires Welsh Gov and Local Authorities to Monitor the use of funding provided to local authorities for respite provision to identify best practice in supporting the needs of the carer and the person who is cared for and ensure this practice is shared. (September 2018 and six monthly review thereafter).	Access to appropriate respite has been raised as an issue during the regional stakeholder discussion. During 2021/22 utilise this funding to review access to respite care for those with dementia and their carers – consider different approaches to providing respite to meet the needs of those with dementia and their carers to align with best practice and the new model of care

KEY: Project Success RAG rating: **GREEN – Project Implemented AMBER – Project Partially Implemented Red – Project Not implemented.** Funding Rationale: **GREEN – Continue RED - Discontinue**

Workstream 3: Complex presentation & end of life care

Ref	Workstream	Project Title	Project success	In line with best practice	In line with the All Wales Dementia Action Plan	In line with Welsh Dementia Standards	Issues to consider	Rationale to continue funding during 2021/22
REG DEM 3a	Regional wellbeing team.	Specialist support to reduce distress presenting as behaviour that challenges	Partially implemented	✓	✓	✓	Staff recruited to except for a psychologist post. Service go live date is required	Launch services and report on outcome's and impact of the service during 2021/22 to provide evidence for future funding

KEY: Project Success RAG rating: **GREEN – Project Implemented AMBER – Project Partially Implemented Red – Project Not implemented.** Funding Rationale: **GREEN – Continue RED - Discontinue**

Conclusion

There are a number of initiatives that have been developed, some are being piloted and some are about to go live as a service.

All initiatives funded by the regional dementia ICF are in line with best practice, the All Wales Dementia action plan and the All Wales Dementia Standards. The development of the regional dementia service model as part of the strategy development currently underway will provide direction as to where to allocate funding more permanently. In the meantime, it would be prudent to continue to fund the existing services that have been successfully implemented, or are about to be implemented whilst also setting up some initiatives that will provide the foundation for supporting the transition to the new model of care, once agreed.

One more thing to consider - the dementia care co-ordination role - the glue

Whilst there is a need to map, review and align community connector, social prescribing and care navigation roles during 2021/21 – it is important to understand that the role of care co-ordination for dementia must not be confused as a function that can be bolted onto another role.

The role of a dementia care co-ordinator requires defining. However, assuming that the ultimate aim is for the whole region to achieve the All Wales Dementia Standards it is important to consider the following standards which could fall under the dementia care co-ordinator role. Elements of the role require professional care and support skills and it could be argued that a new professional role should be developed to deliver the standards, as well as to provide ongoing support pre and post diagnosis, such as with the Scottish model.

The dementia care co-ordinator role would be central to the new model of care.

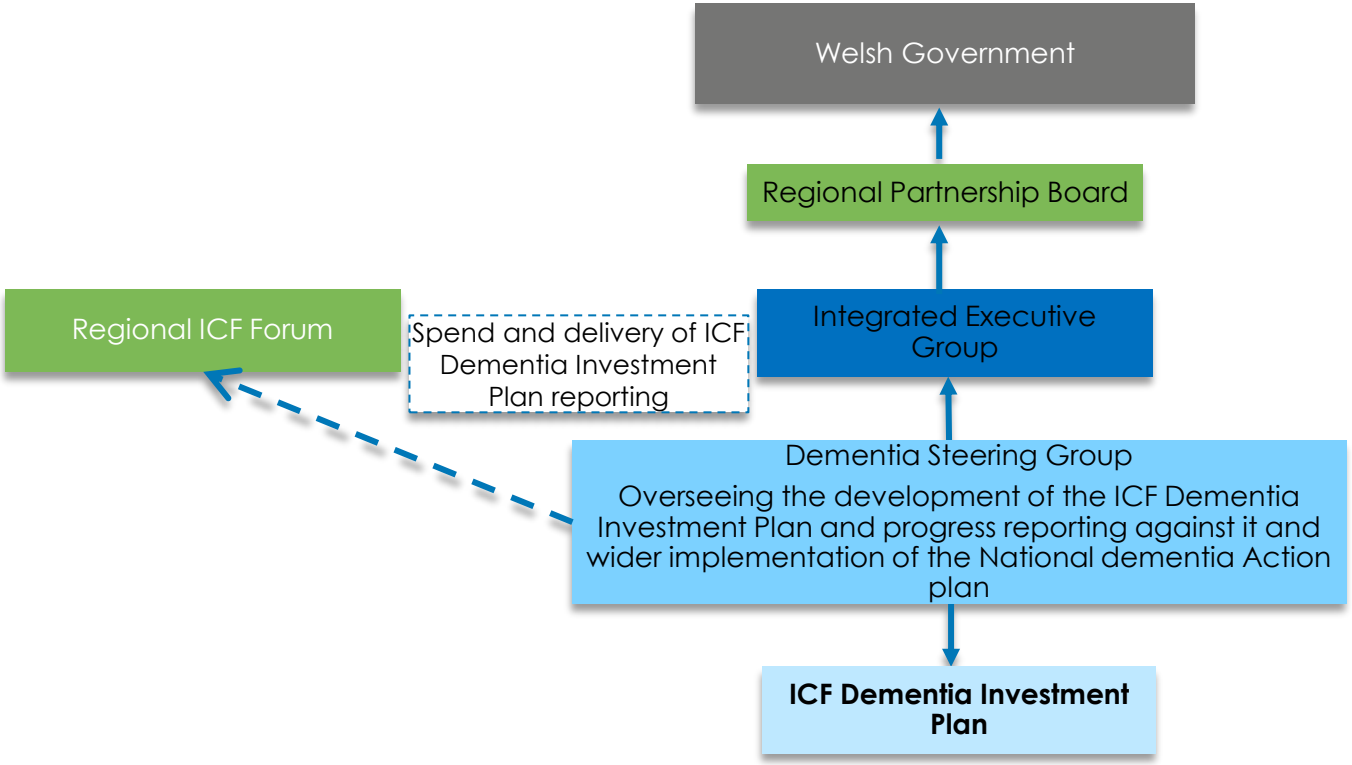
New All Wales Dementia Standards relation to the need for care –co-ordination

- **Standard 7** 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.
- **Standard 8** People living with Mild Cognitive Impairment (MCI) will be offered a choice of holistic services monitoring their physical, mental health and wellbeing, with reviews taking place as a minimum six monthly. This will include a range of options including peer support. Signposting and community resources should be at the centre of all intervention (connects to standard one and three).
- **Standard 9** Within 12 weeks of receiving a diagnosis, people living with dementia will be offered education and information on the importance of physical health activities to support and promote health. (connects to standard one).
- **Standard 10** People living with dementia, carers and families will be offered learning, education and skills training. This offer will be stage appropriate and will be provided at significant parts of a person's journey. It will include a range of peer support and shared experience opportunities, (connects to standard one).
- **Standard 12** of the new dementia standard says: 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. Standard 10 People living with dementia, carers and families will be offered learning, education and skills training. This offer will be stage appropriate and will be provided at significant parts of a person's journey. It will include a range of peer support and shared experience opportunities, (connects to standard one).
- Standard 19 Services will ensure that when a person living with dementia has to change or move between any settings or services, care with supportive interventions will be appropriately coordinated to enable the person to consider and adapt to the changed environment. This will ensure that all care partners will communicate and work jointly with each other to support a seamless transition

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

Current Integrated Care Fund (ICF)Dementia Investment Governance Arrangements



What does good programme management look like?

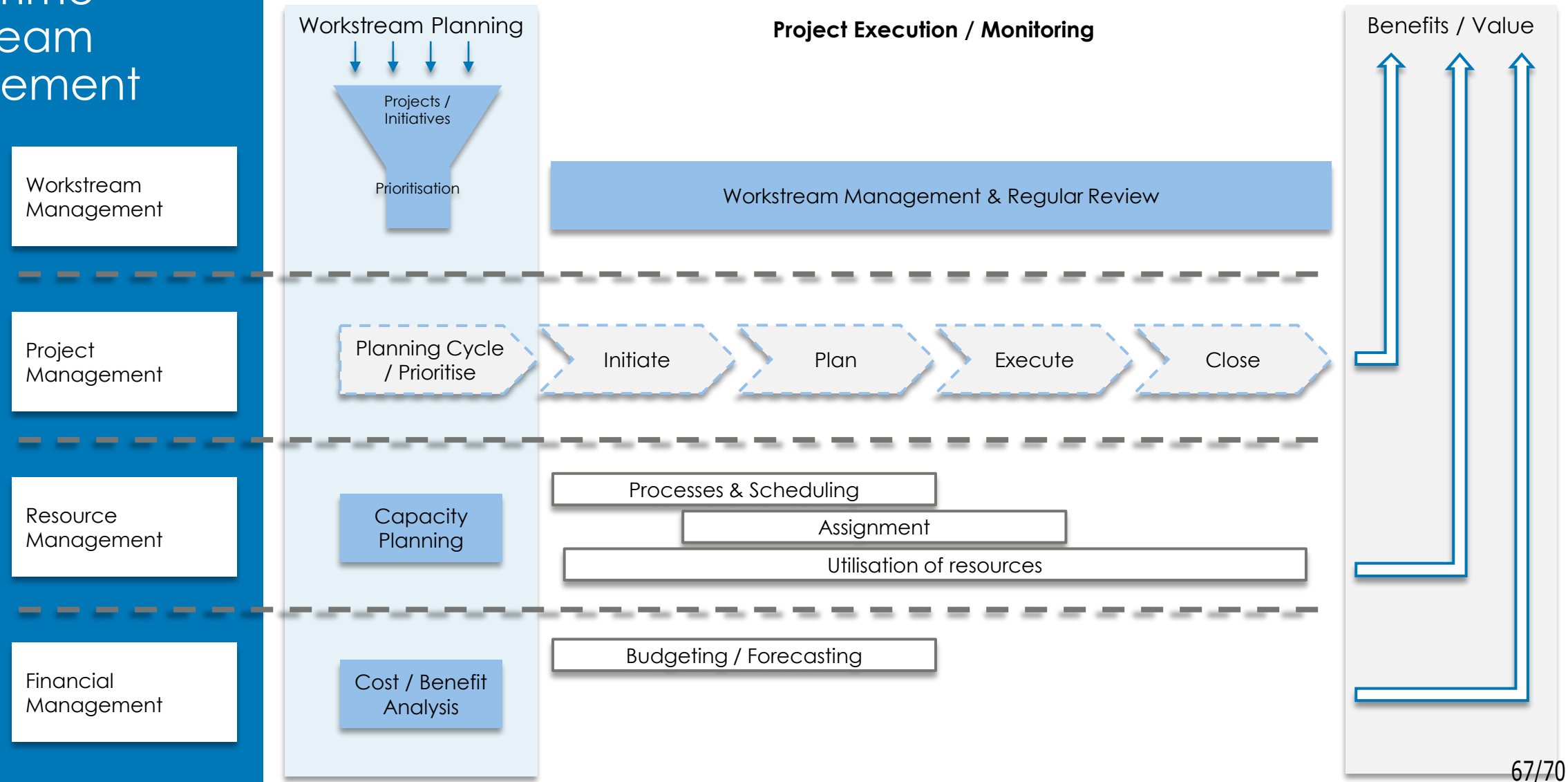
The components of a good programme (1)

	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



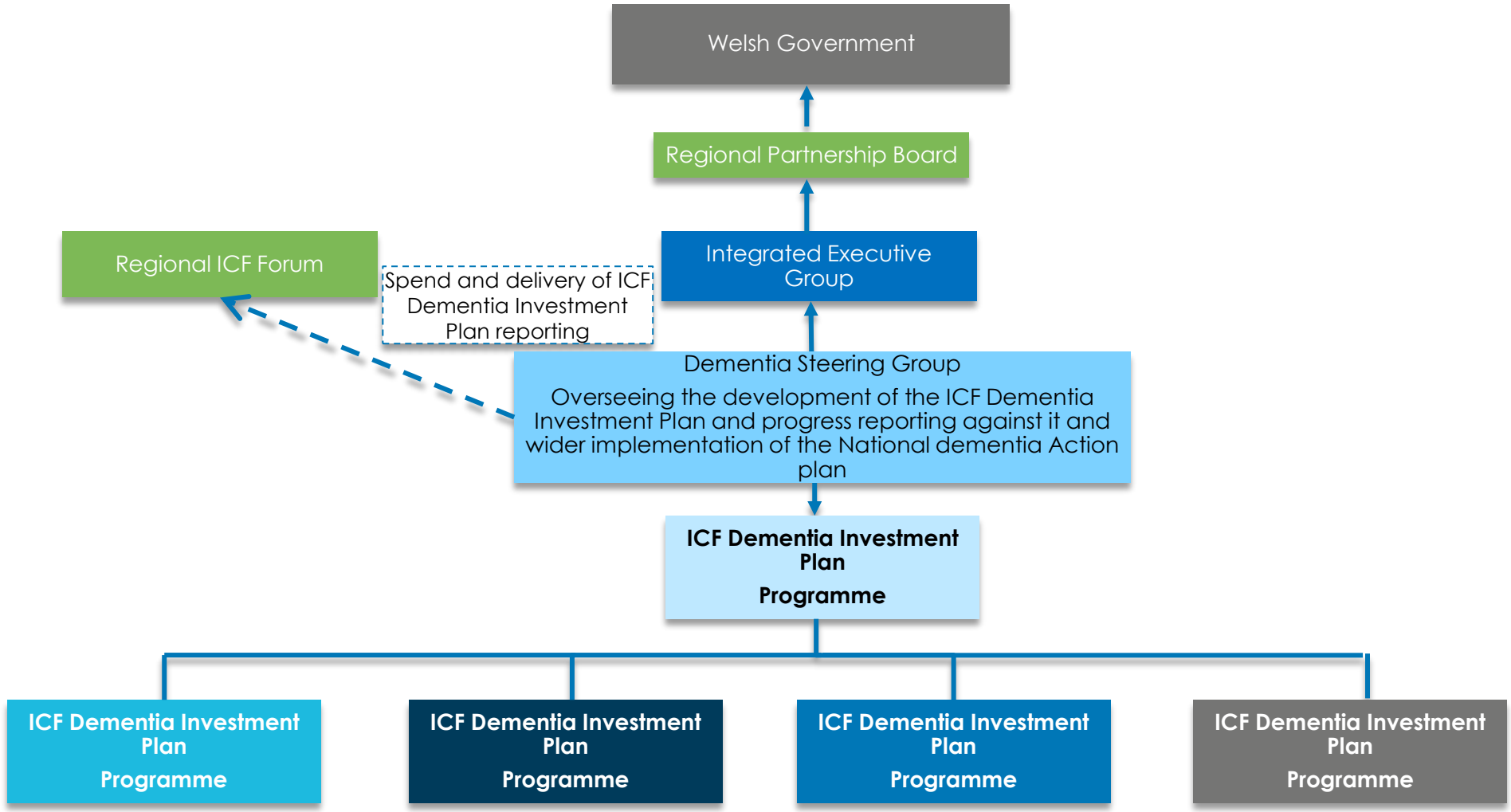
Proposed Delivery Approach: Portfolio Management

The below is an indicative set of workstreams for leading the ICF Dementia Workstreams during 2021/21. Each workstream should be led by a senior leader within the system. Given all services are front line, resources will need to be idenfied to manage the programme and resources will be required over the life of the programme to enable continuation of service delivery whilst staff work to design and develop the services.

	Governance, Strategy Dev and Programme Management PMO	Workstream 1:	Workstream 2:	Workstream 3:
Aim	To develop a strategy and the 'at scale' operating model. Implement strategic leadership. Oversight of performance to drive consistency in decision making and improved care	Enabling the change and improving prevention	Improving diagnosis, early management and wraparound community services - Service delivery	Complex presentation & end of life care
Programmes	• Dementia strategy, vision and service model • WWCP programme governance structure • ICF Demetria programme performance dashboard • Oversight of 2021/22 projects and allocation for 2022 onwards • Enable data intelligence to support decision making & planning	• Develop an integrated, structured approach to skills development • Develop a Dementia Roadmap	• Increase the number of Advanced Scope Practitioners • Extend the application of technology • Establish skilled dementia advice and support – Admiral nurses • Continue to pilot Fulfilled Lives and Virtual Day service and provide robust evidence for rolling out the services across the region if appropriate • Map navigator, social prescribing and community connector type roles develop the business case for dementia case co-ordinator role • Continue with the community connector role in Pembs and share activity and outcomes as part of reporting • Respite - During 2021/22 utilise this funding to review access to respite care for those with dementia and their carers – consider different approaches to providing respite to meet the needs of those with dementia and their carers to align with best practice and the new model of care	• Regional Wellbeing Team - Specialist support to reduce distress presenting as behaviour that challenges

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

Proposed Integrated Care Fund (ICF) Governance Arrangements



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