# PWYLLGOR DATBLYGU STRATEGOL A CHYFLENWI GWEITHREDOL
# STRATEGIC DEVELOPMENT AND OPERATIONAL DELIVERY COMMITTEE

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| **DYDDIAD Y CYFARFOD:**<br>**DATE OF MEETING:** | 24 February 2022 |
| **TEITL YR ADRODDIAD:**<br>**TITLE OF REPORT:** | HDdUHB Palliative & End of Life Care Strategy |
| **CYFARWYDDWR ARWEINIOL:**<br>**LEAD DIRECTOR:** | Jill Paterson, Director of Primary Care, Community & Long Term Care |
| **SWYDDOG ADRODD:**<br>**REPORTING OFFICER:** | Jina Hawkes, General Manager Community & Primary Care & Alison Bishop, USC Lead |

| **Pwrpas yr Adroddiad** (dewiswch fel yn addas)<br>**Purpose of the Report** (select as appropriate) |
|---|
| Ar Gyfer Penderfyniad/For Decision |

## ADRODDIAD SCAA
## SBAR REPORT

### Sefyllfa / Situation

This paper introduces the Palliative & End of Life Care Strategy to the Strategic Development and Operational Delivery Committee (SDODC) that Hywel Dda University Health Board (HDdUHB) commissioned from Attain, Healthcare Consultancy.

SDODC is requested to acknowledge the Strategy and support its presentation to Board in March 2022 for approval.

### Cefndir / Background

In April 2020, in response to the COVID-19 pandemic, Welsh Government issued the COVID-19 Hospital Discharge Service Requirements (Wales), and as a result a regional approach, through the West Wales Care Partnership (WWCP), outlining standards and principles was agreed which sought to describe equitable outcomes for our population across the three Counties, whilst allowing for local variation in delivery.

The WWCP Palliative & End of Life Care Principles (PEOLC) were agreed in September 2020, and this document highlighted that whilst there were some reference documents available in Wales and across the UK, there was no All Wales PEOLC Strategy nor a related HDdUHB Strategy.

The WWCP EOLC principles clearly articulated the desire to adopt the six positive ambitions defined in the National Palliative & EOL Care Partnership Ambitions for Palliative and End of Life Care framework[1]. Whilst this is a document produced for NHS England, these ambitions are equally valid for the population of Wales;

1. Each person is seen as an individual – what matters to me

[1] National Palliative & EOL Care Partnership (2015) Ambitions for Palliative and EOL Care; A national framework for local action 2015 - 2020

2. Each person gets fair access to care – regardless of who I am, where I live or the circumstance of my life

3. Maximising comfort and wellbeing – help me to be as comfortable and as free from distress as possible

4. Care is co-ordinated – getting the right help from the right people at the right time

5. All staff are prepared to care – staff bring empathy, skills & expertise and give me competent, confident & compassionate care

6. Each community is prepared to help – we all have a role to play in supporting each other in times of crisis and loss

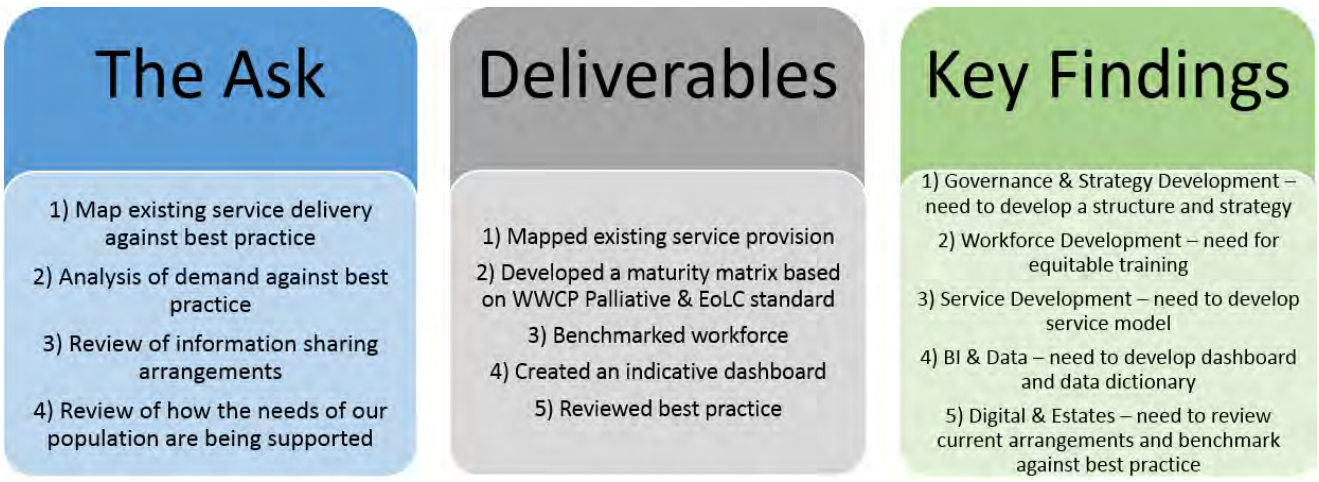
The Marie Curie report[2] assessing palliative care needs across the UK nations, confirmed that palliative care need is growing over time, and suggests that estimates of palliative care need at 75-80%, as included in the Wales report, do not take into account this increased level of need.

## Asesiad / Assessment

It was therefore considered essential that HDdUHB has a robust Strategy in place to ensure everyone at the end of life is able to access the specialist care and holistic support they need, and that this Strategy takes into account robust estimates of palliative care need and develops a robust and sustainable workforce plan to meet these increasing needs.

Utilising All Wales Palliative Care funding, HDdUHB commissioned an external review by Attain of palliative care and end of life services. This discovery phase was undertaken January – April 2021 and the key findings are outlined below:

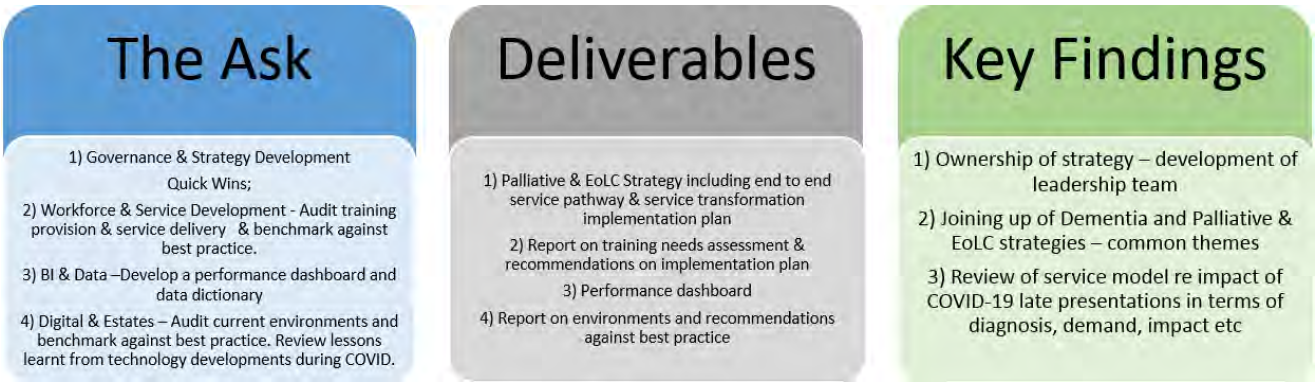
**Discovery Phase 1 January – April 2021**




One of the key findings from this discovery phase was the absence of a HDdUHB Strategy, therefore to bridge this gap, a further phase was commissioned to work with Attain to develop this Strategy for the Health Board. This work was undertaken with engagement from a wide range of stakeholders during spring/summer 2021:

[2] Marie Curie (2016) An Updated Assessment on Need, Policy and Strategy – Implications for Wales

**Strategy Development Phase 2 April - June 2021**

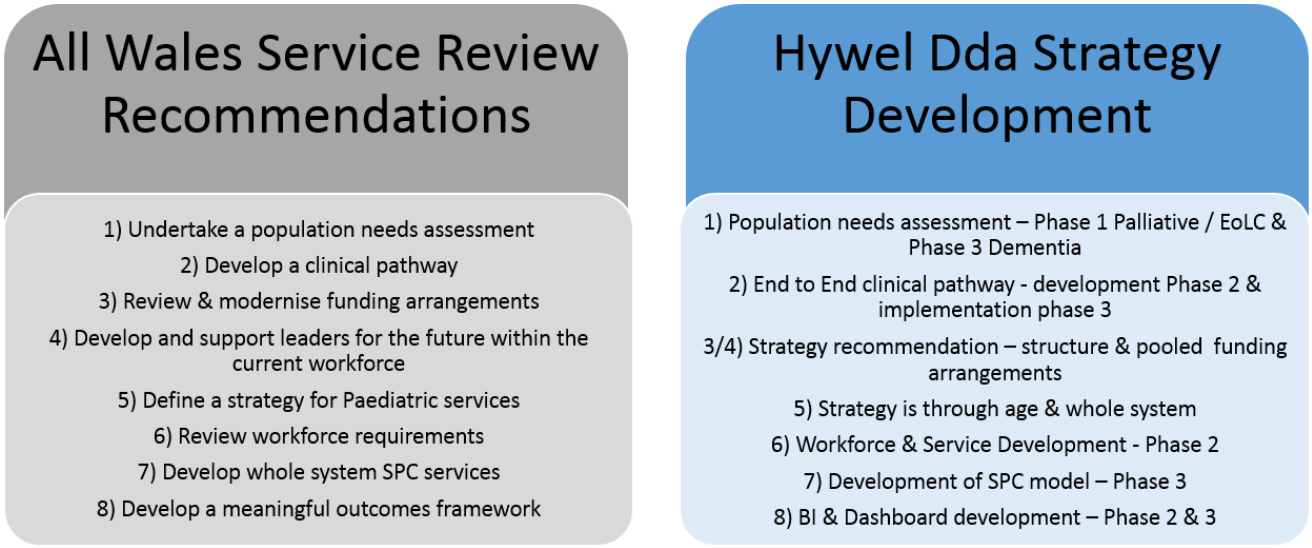



The HDdUHB PEOLC steering group has approved the Strategy document, and the final phase of the commissioned work is ongoing to develop the service specification for PEOLC and associated workforce plan.

During phase 2, Attain were also commissioned by the WWCP to undertake an external review of dementia care across the region, and due to the overlap between aspects of the services, this final phase of work has been jointly commissioned between HDdUHB and the WWCP to bring the two pieces of work together to ensure the maximum benefit for our population.

The PEOLC priorities are in line with the Ambitions for Palliative & EOLC National Framework, and the 2019 National Audit of Care at the End of Life builds on the initial continuous improvement programme.

An All Wales PEOLC service review has recently been undertaken and a review of the final report document has been undertaken to ensure that the local Strategy will align to the direction of travel across Wales in the absence of an All Wales Strategy;




## Argymhelliad / Recommendation

SDODC is requested to:

- **NOTE** the Strategy and support its presentation to the March 2022 Board for approval.

| **Amcanion: (rhaid cwblhau)<br>Objectives: (must be completed)** | |
|---|---|
| Committee ToR Reference:<br>Cyfeirnod Cylch Gorchwyl y Pwyllgor: | 3.4 Seek assurance on the development of the Health Board's Integrated Medium Term Plan (IMTP), based on robust business intelligence and modelling, and assure the development of delivery plans within the scope of the Committee, their alignment to the Health Board's Plan/IMTP and the Health Board's strategy and priorities (PO 3E). |
| Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol:<br>Datix Risk Register Reference and Score: | Not Applicable |
| Safon(au) Gofal ac Iechyd:<br>Health and Care Standard(s): | 5. Timely Care<br>3.1 Safe and Clinically Effective Care<br>4. Dignified Care |
| Amcanion Strategol y BIP:<br>UHB Strategic Objectives: | 2. Working together to be the best we can be<br>3. Striving to deliver and develop excellent services<br>4. The best health and wellbeing for our individuals, families and communities<br>5. Safe sustainable, accessible and kind care |
| Amcanion Llesiant BIP:<br>UHB Well-being Objectives:<br>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<br>4. Improve Population Health through prevention and early intervention, supporting people to live happy and healthy lives<br>5. Offer a diverse range of employment opportunities which support people to fulfill their potential |

| **Gwybodaeth Ychwanegol:<br>Further Information:** | |
|---|---|
| Ar sail tystiolaeth:<br>Evidence Base: | Welsh Government (WG) 2017 PEOLC Delivery plan<br>WG (2008) Palliative Care Planning Group Wales Report to the Minister for Health & Social Services<br>National Palliative & EOL Care Partnership (2015) Ambitions for Palliative and EOL Care; A national framework for local action 2015 – 2020<br>WG (2020) COVID-19 Hospital Discharge Service Requirements (Wales)<br>HDdUHB (2016) End of Life Delivery Plan<br>HDdUHB (2019) Together for Health Delivering End of Life Care<br>Marie Curie (2016) An Updated Assessment on Need, Policy and Strategy – Implications for Wales<br>WWCP (2020) PEOLC Principles |
| Rhestr Termau:<br>Glossary of Terms: | Explanation of terms is included within the report |

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| Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Datblygu Strategol a Chyflenwi Gweithredol: Parties / Committees consulted prior to Strategic Development and Operational Delivery Committee: | Palliative Care Steering Group<br>Integrated Executive Group/ Regional Partnership Board |

| **Effaith: (rhaid cwblhau)<br>Impact: (must be completed)** | |
|---|---|
| **Ariannol / Gwerth am Arian:<br>Financial / Service:** | All accounted through funding streams outlined above |
| **Ansawdd / Gofal Claf:<br>Quality / Patient Care:** | Equitable outcomes for the population across all ages. |
| **Gweithlu:<br>Workforce:** | Not Applicable |
| **Risg:<br>Risk:** | Not Applicable |
| **Cyfreithiol:<br>Legal:** | Not Applicable |
| **Enw Da:<br>Reputational:** | The Strategy is the first of its kind in Wales. |
| **Gyfrinachedd:<br>Privacy:** | Not Applicable |
| **Cydraddoldeb:<br>Equality:** | The Strategy reflect the needs of the population. |

# Hywel Dda University Health Board (HDuHB) Palliative and End of Life Care (PEOLC) Strategy

Attain
Improving health and wellbeing

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Hywel Dda University Health Board

September 2021 v2.1

This strategy should be read in in conjunction with the Attain EOLC best practice examples report published February 2021 and the HDuHB palliative care discovery final report v2.7 published May 2021

**'To provide excellent palliative and end of life care across West Wales enabling people to be cared for and die in their preferred place of care'**

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# Background

Hywel Dda University Health Board (HDuHB) is comprised of three Counties - Carmarthenshire, Ceredigion and Pembrokeshire. Each County operates Palliative and End of Life Care (PEOLC) services configured to their individual geography, population need and assets. However, recently, a regional approach, through the West Wales Care Partnership (WWCP), outlining standards and principles has been agreed which seeks to align the three Counties in meeting equitable outcomes for the population across all ages.

The HDUHB PEOLC Strategy development programme commenced with a Discovery Phase as a precursor to formal strategy development.

The Discovery Phase provided evidence and insight into:

- National and international best practice
- Benchmarking (via use of a maturity matrix) of the "as is" position across the region, which identifies different practices and gaps versus the best practice articulated in the West Wales PEOLC Principles (Published October 2020)
- Data and Business Information gaps, resulting in weaknesses in the evidence base, inhibiting effective decision making and service transformation

The Discovery Phase, founded on deep stakeholder engagement, energised ownership and commitment to deliver, has been sustained while this strategy has been developed. The Discovery Phase also demonstrated that there were a range of short term improvements which should be undertaken because they will benefit service delivery and which should not wait for a fully signed-off strategy.

Building on the key outcomes from the Discovery Phase, the next phase of work took place over a 3-4 month period and addressed both integrated Strategy Development and Continuous Improvement, utilising a programme approach with key workstreams and continued deep stakeholder engagement.

This strategy is aspirational and sets out the collective ambitions we want to achieve across Hywel Dda to improve PELOC for our citizens. In developing this strategy we have worked with organisations that provide PEOLC services, their staff, local voluntary organisations and other partners. We have also considered previous research and sensitively carried out our own insight work with individuals who are receiving PEOLC and their relatives. Their experiences have helped ensure individuals, their families and carers are at the centre of our strategy, vision and service model. It is now for HDuHB services and local partners to work together to continue to deliver these improvements for their local communities. *N.B. There is a separate report summarising progress made with the Continuous Improvement Programme.*

# Project requirements and activities

Below summarises the strategy development project requirements, the outcomes from the work undertaken and key actions.

## The Ask:

1. Strategy development:
- Deep stakeholder engagement through structured interviews, groups and workshops – to be agreed per county and a final strategy summary session across all three counties, resulting in a PEOLC vision and service pathway.
- Online surveys tailored for children, young people and adult patients, parents/carers of children and young people and partners of adult patients.
- Analysis of service demand for specialist palliative care and workforce capacity.

2. A final strategy to include:
- A PEOLC vision and end to end service pathway.
- A service transformation programme plan
- Alignment of priorities with regional ICF funding.

## Attain have:

1. Strategy development:
Due to the limitations of COVID-19 and the ability to meet in person, Attain:
- Carried out a series of 5 workshops during May 2021.
- Summarised the themes stemming from the interviews with stakeholders in phase 1, together with interviews with patients and carers of all ages.
- Developed 4 patients' and carers' surveys to enable further inputs.
- Worked with colleagues to develop a high-level strategy, service vision and model, based on best practice.
- Included a summary of current and future population demand and prevalence - the impact of demand on the workforce cannot be determined at this stage and will require further analysis.

2. The strategy also includes:
- A service vision and end to end pathway, plus recommendations in relation to implementation of the new service model. However, the extent of further funding allocation is not known at this time.
- Recognition that stakeholders have identified that COVID-19 has impacted timely diagnosis due to late presentations, but the extent of this impact is not fully known at this stage.

## Key Recommendations:

1. Ownership of strategy, implementation of the service vision and model:
- Once formally approved by the HDuHB, to realise the strategy and service vision, the new service model will require implementation.
- The strategy provides a series of priorities which is a significant programme of work that will require resourcing.
- Given the similarities with the developing dementia strategy and service model, it would be more effective to join up efforts to develop the dementia strategy along with the implementation of the PEOLC new service model.
- HDuHB have approved the recruitment of a clinical lead to work as part of a triumvirate team to oversee the implementation of the new strategy through pooled budgets across the region.
- The strategy and service model should be reviewed once information is available regarding the impact of COVID-19 upon late presentations and diagnosis and the probable increase in demand on PELOC services.

# What is Palliative Care?

Palliative care has been defined by the World Health Organization as 'an approach that improves the quality of life of patients and their families facing the problems associated with life limiting illness, through the prevention of, and relief of, suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.'

Palliative care as defined in the Sugar report can be split into 2 categories;
1) General palliative care, delivered by health professionals in a generalist setting
2) Specialist palliative care, delivered by specialist multi-disciplinary teams dedicated to palliative care

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Source: WEST WALES CARE PARTNERSHIPS PALLIATIVE AND END OF LIFE CARE PRINCIPLES

# What is end of life care?

People can receive palliative care at any stage in their illness. Having palliative care doesn't necessarily mean that the person is likely to die soon – some people receive palliative care for years. People can also have palliative care alongside treatments, therapies and medicines aimed at controlling their illness, such as chemotherapy or radiotherapy.

However, palliative care does include caring for people who are nearing the end of life – this is sometimes called end of life care.

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting, terminal, or fatal condition. Even if the prognosis is ambiguous or unknown. Those approaching end-of life will be considered likely to die during the forthcoming days, weeks or months. End-of-life care is care needed for people who are likely to die in the forthcoming months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.

End of life care involves treatment, care and support for people who are nearing the end of their life. It's an important part of palliative care.

Source: WEST WALES CARE PARTNERSHIPS PALLIATIVE AND END OF LIFE CARE PRINCIPLES

# 2. Population needs analysis summary

# Population is up…

Hywel Dda has an aging population that is **above the Welsh average** for over 65s.

Hywel Dda Over **75% aged 85+ have 2 or more** long term conditions.

Increasingly complex and longer term end of life care.

## UP 0.5% by 2025, 2% by 2040

The population of Hywel Dda is increasing overall

## Ageing population

The over 65 population is set to increase by 6% over 5 years and a massive 27% by 2040

## Over 85s become over 10% of the population

And over 65s will become over a third of the population by 2040

## Care becoming more complex

Pre-Covid the leading individual causes of death in Hywel Dda were Dementia and Heart disease representing 11% each** (UK wide dementia 12.7%)

Hywel Dda Adult population is decreasing, **overall population increasing***.

*Source*: ONS, *Ceredigion total population will decrease but elderly population increase

**2019 NOMIS, defined by ONS using ICD10, high variation across counties with Ceredigion lowest at 9% dementia and Carmarthenshire highest at 11.7%, likely to increase all around due to ageing

# Conditions and mortality

Dementia accounts for 12.7% of deaths and is the leading cause of death across the UK

In Hywel Dda dementia is closer to 11% with variation across counties largely due to age profiles

IHD is still a main cause of death in the UK despite falling as a proportion from 14% (2010) to 10.4%

IHD has similar proportions to dementia across Hywel Dda at 11% on the whole

There are over 14,000 people in Hywel Dda on GP registers with a diagnosis of cancer at some stage

There are over 4,800 people in Hywel Dda registered with Heart Failure

1 in 8 deaths across England and Wales were attributed to Dementia in 2018

Alzheimer's society expects the number of dementia patients living alone will double by 2040

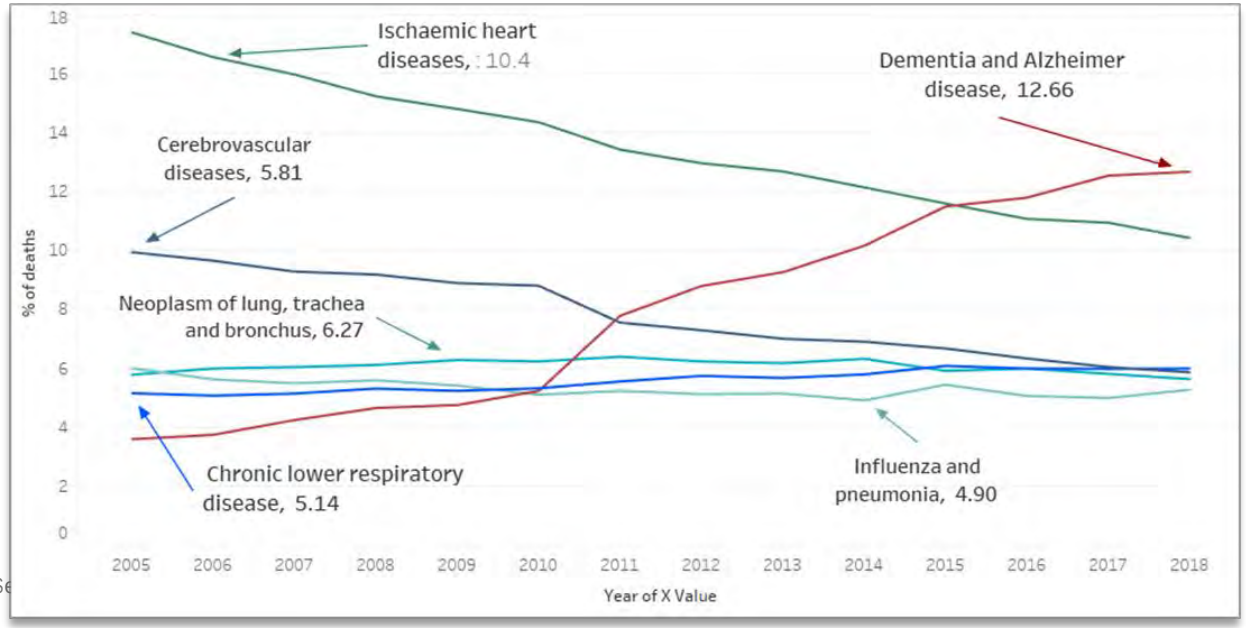
Ischaemic heart disease remains the leading cause of death for men, overall

9,000 people on the GP register, in Hywel Dda had a diagnosis of COPD

COVID-19 impacted mortality resulting in an increase in excess deaths of around 14% across England and Wales

It is, as yet unknown what the future impact of COVID-19 on mortality and end of life care will be

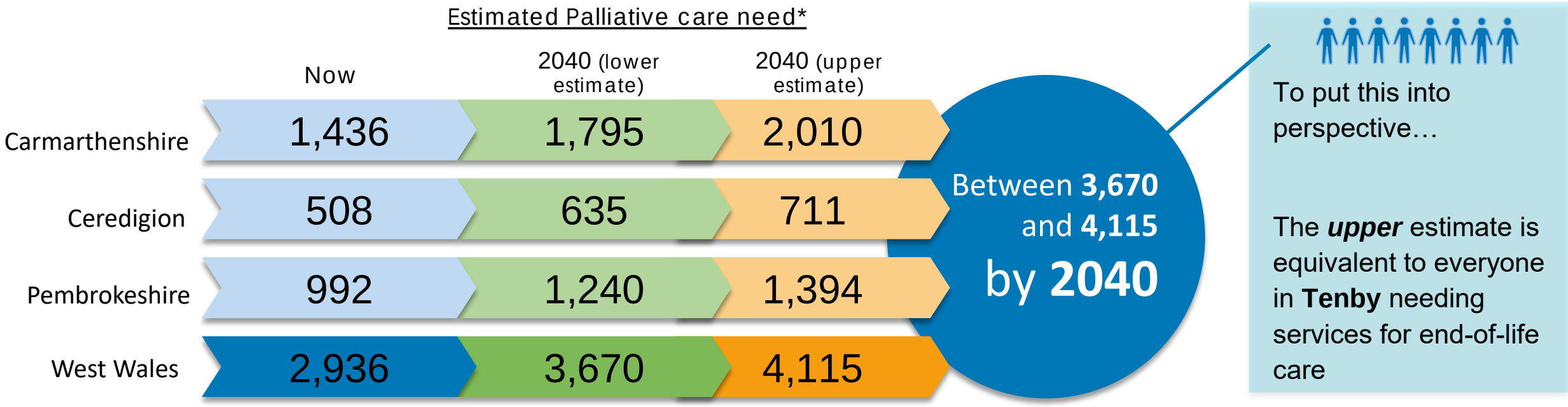
Leading causes of mortality, UK up to 2018 (showing most recent % of total deaths)



# Mortality and palliative care

From the All Wales PEOLC Delivery Plan 2017, it is estimated that 0.75% of the Welsh population have palliative care needs at a given time. Further, "The [plan] suggests an estimated prevalence rate for children and young people likely to require palliative care services as 15 per 10,000 population aged 0–19" this equates to 12-13 children in Hywel Dda.

It is indicated that over 65%* of people who are dying or die will have a palliative care requirement and the number of people needing palliative care will grow by 25% by 2040*.




NB: CYP data included in totals: Numbers are very low and in cases where the 5 year age grouping was below 5, numbers were supressed and automatically rounded up to 5. This means that this number is likely a slight over estimation of deaths for 0-19 year olds but not a significant impact

* How many people will need palliative care in 2040? Past trends, future projections and implications for services - S. N. Etkind et al – this paper was used for estimates, 25% growth from 2014, data above is 2019, however 25% as report suggested it could be as high as 42% from 2014-2040

# 3. What does best practice tell us?

# The Welsh Government's PEOLC delivery plan

Published in March 2017, Wales was the first of two nations in the United Kingdom to have a current and overarching delivery plan for palliative and end of life care.

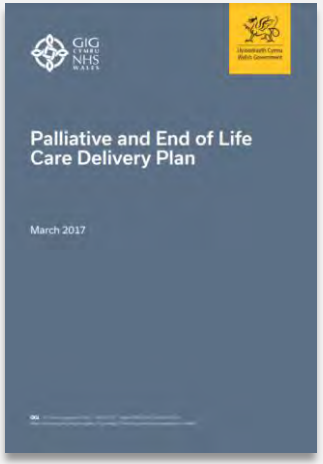
Reports published during the term of the first End of Life Care Delivery Plan also highlighted areas where improvement is required. Living and Dying with Dementia in Wales: Barriers to Access' Alzheimer's Society Wales Marie Curie 2015 and People with a Learning Disability 'A Different Ending: Addressing Inequalities in End of Life Care' Care Quality Commission 2016, identified barriers including access to care for people living with learning disabilities and dementia, and a lack of effective advance care planning and timely diagnosis for both groups.

The need to improve access to palliative care services for Black, Asian and Minority Ethnic (BAME) and Lesbian Gay Bisexual Transgender (LGBT) communities were highlighted in South East Cardiff Marie Curie (2014) and "Hiding who I am" 'The reality of end of life care for LGBT' people Marie Curie (2016) respectively.

The plan recognises there is a need to adopt a combined approach of Advance Care Planning, shared decision making and training for healthcare professionals in this field to support these patients and their families and carers, and to learn the best ways to meet the individual's needs.

The PEOLC Delivery Plan has clearly defined the specific priorities for Health Boards for the period 2017-2020 across 7 key delivery themes;

1. Supporting Living and Dying Well,
2. Detecting and identifying patients early,
3. Delivering fast, effective End of Life Care,
4. Reducing the distress of terminal illness for the patient and those close to them,
5. Improving Information,
6. Targeting research,
7. Education.




N.B. The Welsh Government have recently carried out a stocktake summarising the progress made in delivering the plan which is due for publication soon.



Source: https://gov.wales/sites/default/files/publications/2019-01/palliative-&-end-of-life-care-delivery-plan-2017_0.pdf

# Ambitions for PEOLC Care: A national framework for local action 2015 - 2020.

In 2015 in England the National PEOLC Partnership (NPEOLCP) published the Ambitions for PELOC: A national framework for local action 2015 -2020.

Although the ambitions focus on the experience of the dying person, the partners' concern is broader. Each statement should also be read as an ambition for carers, families, those important to the dying person, and, where appropriate, for people who have been bereaved.

The main aim of the framework is to provide the foundations and building blocks which local health and social care leaders can use to build accessible, responsive, effective and personal care needed at the end of life.

HDuHB have recently developed the West Wales Care Partnerships PEOLC principles building on the foundations of the Ambitions for palliative and EOLC framework (published October 2020) which recognise that whilst the National Framework is a document produced for NHS England, the ambitions and building blocks are equally valid for the population of Wales.

Along with the Welsh Governments 7 key delivery themes, the West Wales Partnership have therefore adopted the framework ambitions and building blocks and have confirmed that the HDuHB's Primary and Community Care Guidelines and the Hospital Discharge Requirements align with these foundations and building blocks and provide further clarity.

Attain

## Ambitions for Palliative and End of Life Care

01 **Each person is seen as an individual**
*I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.*

02 **Each person gets fair access to care**
*I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*

03 **Maximising comfort and wellbeing**
*My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.*

04 **Care is coordinated**
*I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.*

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

06 **Each community is prepared to help**
*I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*

More information on the ambitions for palliative and EoLC can be found here: https://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

# The building blocks to deliver the Ambitions for PEOLC Care national framework.

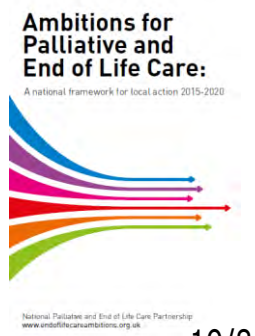
To realise the ambitions, the NPEOLCP identified eight foundations/building blocks that need to be in place. They are all necessary and underpin the ambitions.

These foundations are the pre-conditions for delivering the rapid and focused improvement that the Partnership seeks.

For West Wales, they are the starting point from which the new and collective endeavour must be built.

- **Each person is seen as an individual**
  - Honest and well informed conversations
  - Clear expectations
  - Helping people take control
  - Systems for patient centred care
  - Access to social care
  - Integrated care
  - Good EoLC including bereavement
- **Each person gets fair access to care**
  - Community partnerships
  - Unwavering commitment to achieve equity
  - Population based needs assessment
  - Person centred outcome measurement
  - Using the data to guide care and drive change
- **Maximising comfort and wellbeing**
  - Recognising and addressing distress whatever the cause
  - Skilled assessment and symptom management
  - Priorities for care of the dying person
  - Access to specialist palliative care when needed
  - Rehabilitative palliative care
- **Care is co-ordinated**
  - Shared records
  - System wide response
  - Clear roles and responsibilities
  - Everyone matters
  - Continuity in partnership
- **All staff are prepared to care**
  - Professional ethos
  - Knowledge based judgement
  - Awareness of legislation
  - Support and resilience
  - Using new technology
  - Executive governance
- **Each community is prepared to help**
  - Compassionate and resilient communities
  - Practical support
  - Public awareness
  - Volunteers

More information on the building blocks to support the delivery of the ambitions for PEOLC can be found here: https://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf



# Best practice summary

As part of our best practice review we researched a wide range of current local, national and international examples of best practice focusing on the following areas that will be key to any new service development

**The common workforce delivery model:**

Should be adopted in line with the Sugar Report June 2008 where staff across the region provide:

1) General palliative care, delivered by health professionals in a generalist setting e.g. community and secondary care
2) Specialist palliative care, delivered by specialist multi-disciplinary teams dedicated to palliative care

**Services models:**

- To achieve consistency in provision, the West Wales Care Partnership should agree the PEOLC pathway for the area in line with best practice
- The HDuHB should consider whether the best practice examples, such as the Midhurst and SWAN/Cygnet models should be adopted

**Training:**

- All healthcare workers and volunteers, regardless of role, should have access to education and training in EOL and bereavement, with the level being dependent on the nature of their role and their exposure to death and dying

**Use of technology:**

- In addition to home care, telehealth and remote patient monitoring (RPM) has numerous benefits to patients across the healthcare spectrum, including those receiving palliative care

**Supporting Carers:**

- Partners should review the learning from caring for those with dementia, COIVD-19 and for those who are bereaved and think about whether they can be applied to current service delivery, or built into relevant strategies and/or service transformation plans
- All environments where end of life care occurs should provide appropriate places to support the families and carers

**Bereavement:**

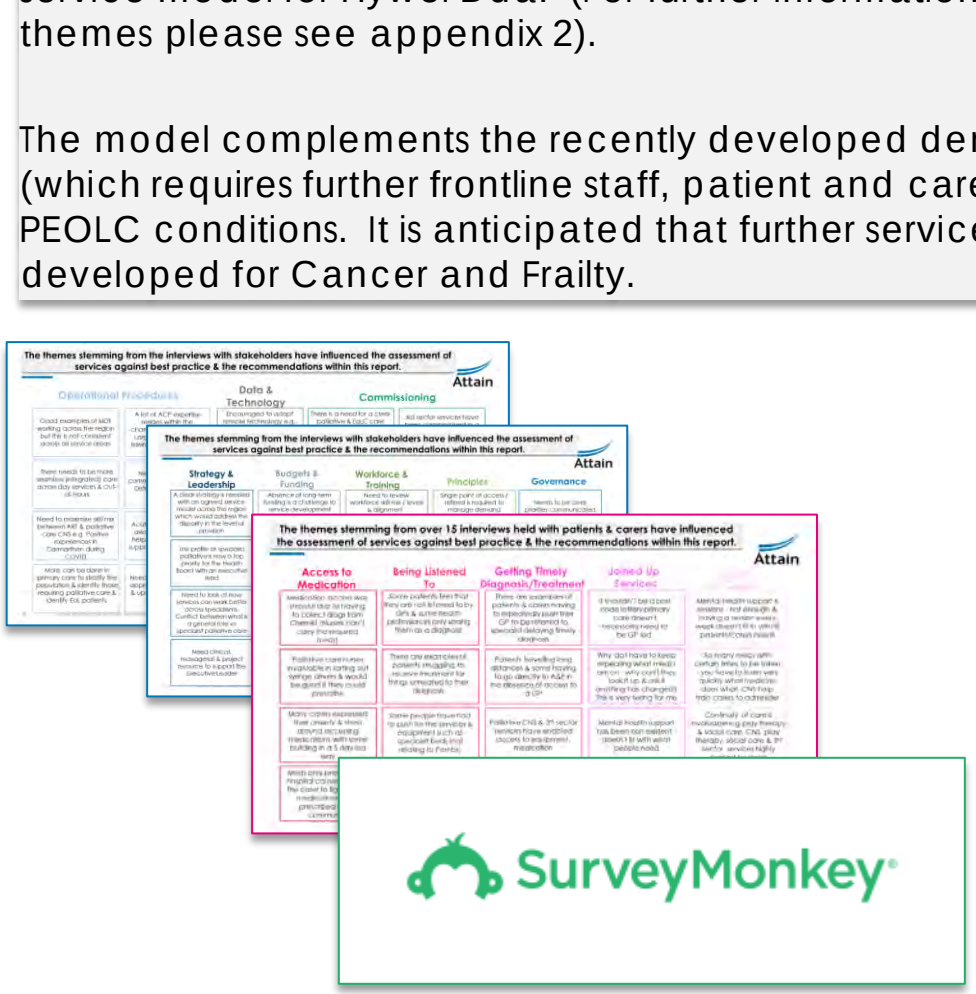
- Strategies across the globe include the importance of engaging with the local community, spiritual and other leaders to build bereavement capacity within the community
- Adopt compassionate communities' policies and practices, to support bereaved people
- A framework for bereavement currently being developed should be included into all relevant service specifications and built into standard operating procedures across all services

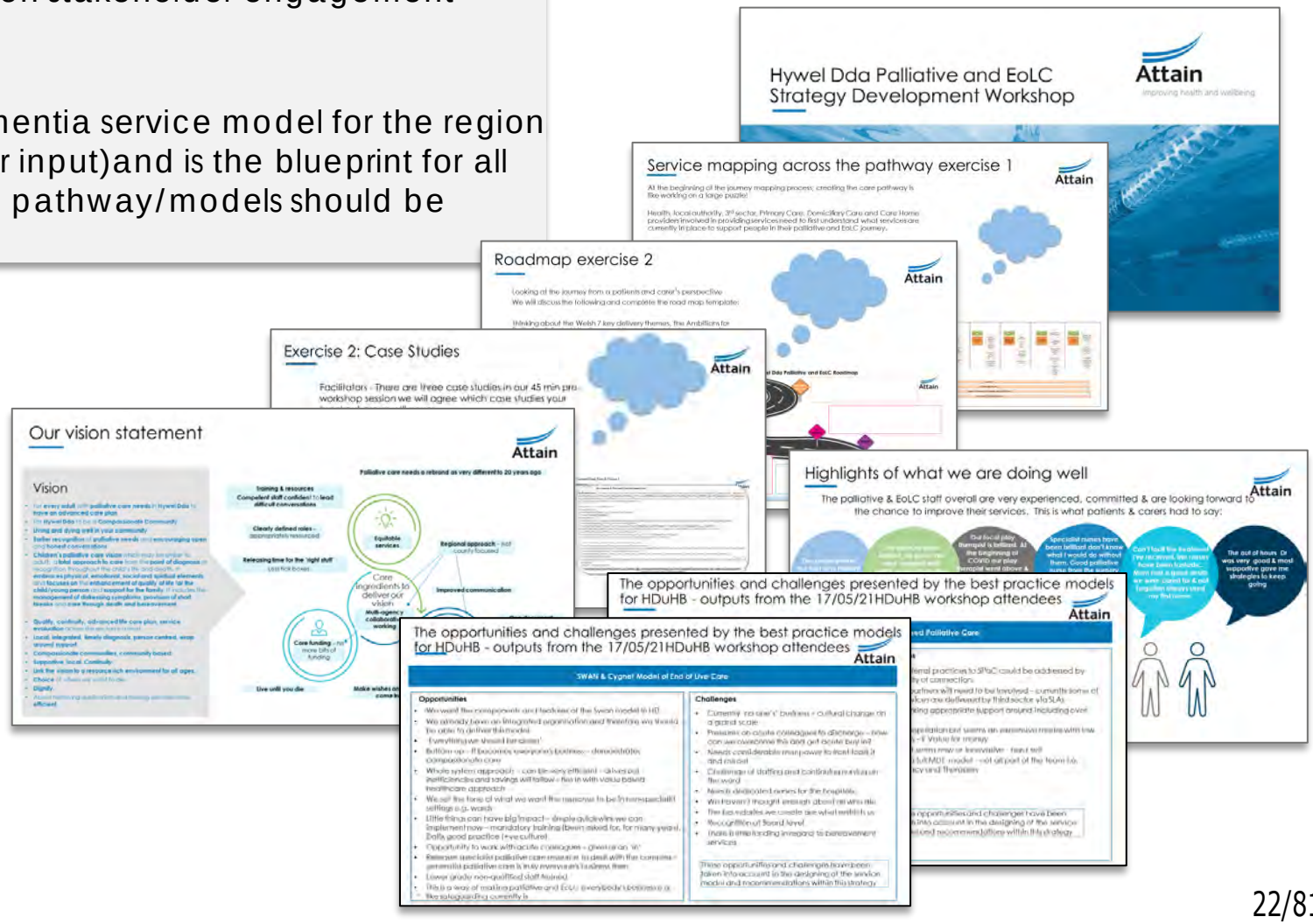
# 4. Our service model pathway

# Developing the Hywel Dda PEOLC service model blueprint

Following a series of workshops held during May 2021, interviews with stakeholders in phase 1, together with interviews with patients and carers of all ages, plus further input via patients' and carers' surveys, we have developed the following palliative and EoLC service model for Hywel Dda. (For further information on stakeholder engagement themes please see appendix 2).

The model complements the recently developed dementia service model for the region (which requires further frontline staff, patient and carer input)and is the blueprint for all PEOLC conditions. It is anticipated that further service pathway/models should be developed for Cancer and Frailty.



# Hywel Dda PEOLC service vision

**'To provide excellent palliative and end of life care across West Wales enabling people to be cared for and die in their preferred place of care'**

Specialist palliative 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 PEOLC vision, strategy and service model in line with WWCP PEOLC principles
- Integrated governance arrangements
- Strategic and collaborative patient/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
- Health Board and provider (including 3rd Sector) alliances, delivering services into local networks and enabling frontline integration
- Shared system transformation programmes and plans
- Consideration of local risk and reward mechanisms, alignment of incentives, and new contractual forms

- Provision of primary care services at scale
- Staff across organisations trained and working together across the region in an integrated way to best meet the needs of the population
- Interpret population health data and patient/family feedback, design services for integrated networks and draw in support from wider services

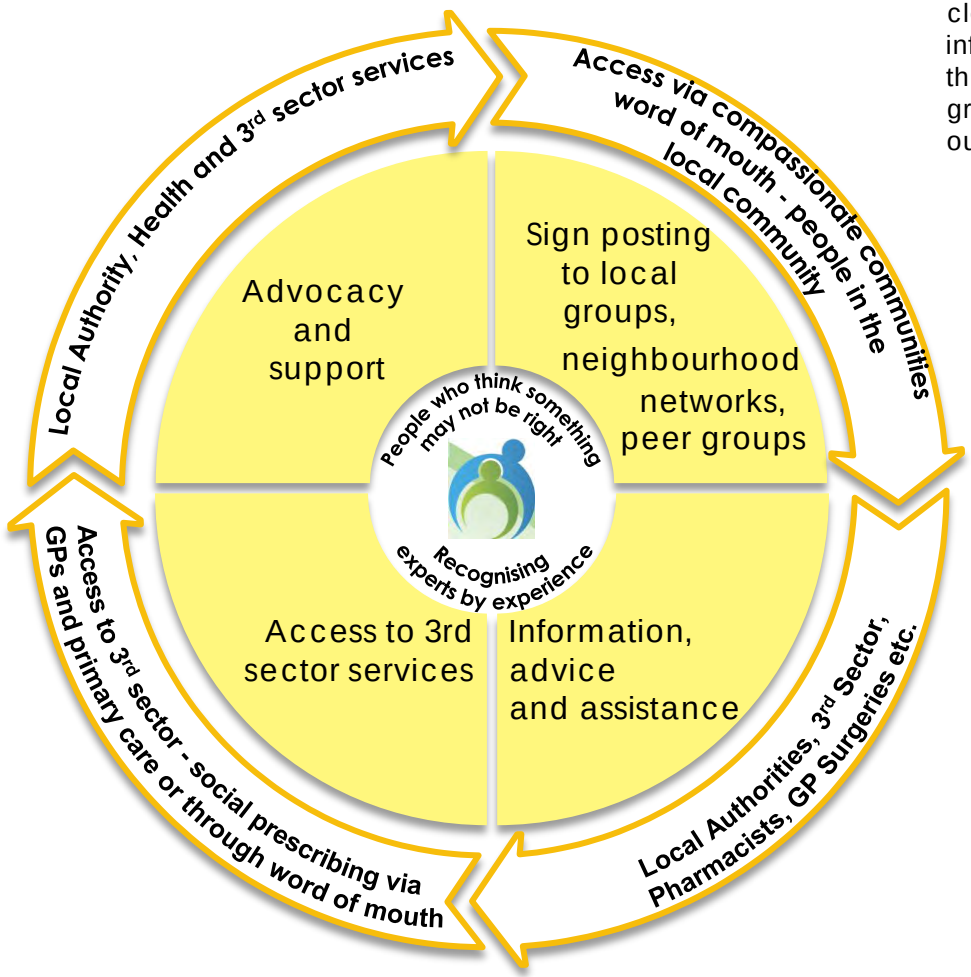
Source: West Wales Care Partnership Palliative and EoLC Principles 23/10/20

# What good looks like for Hywel Dda – The PEOLC service model pathway

Attain

Looking after our physical and mental wellbeing, raising awareness and understanding


Getting help and support in the early stages



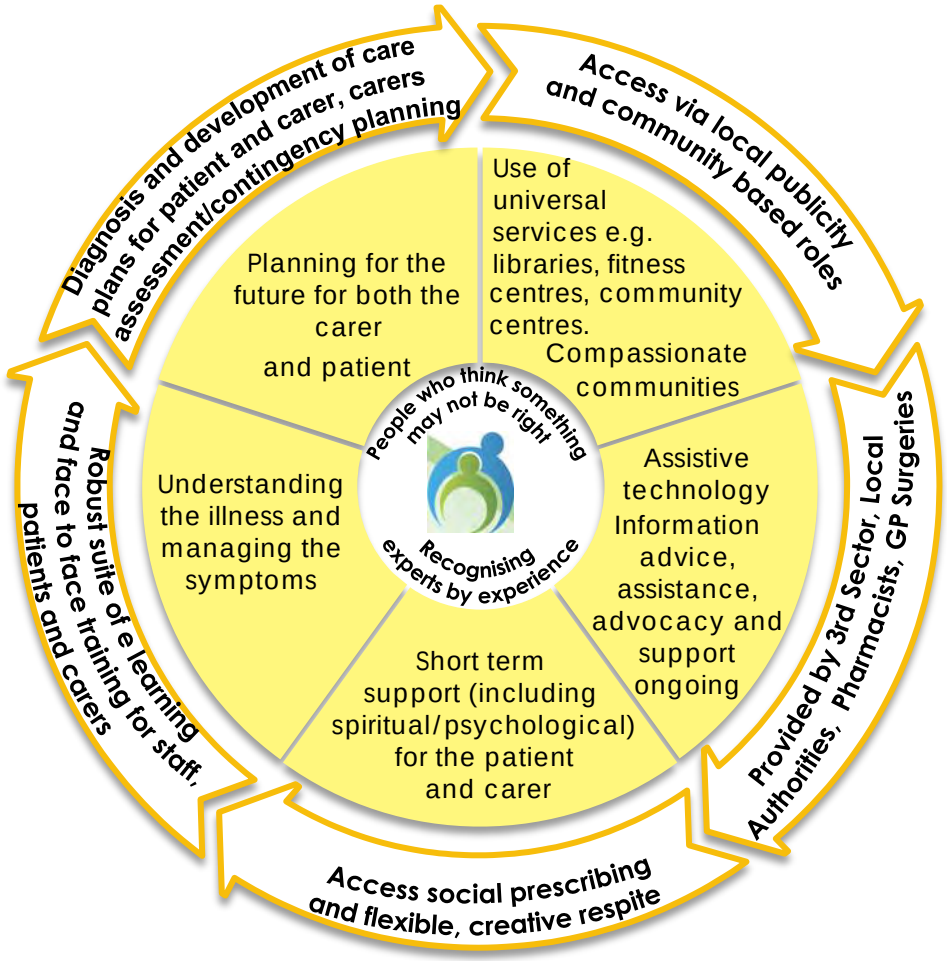

- Carers and palliative care patients need clear and accessible information connecting them to local peer groups for support at the outset.

Underpinned by training across all staff

# What good looks like for Hywel Dda – The PEOLC service model pathway

## Identification, assessment and diagnosis

- Enabling generic services (e.g. social work, domiciliary care, care homes, district nursing, OT, physio etc.) to support people with a palliative diagnosis - education - what signs to look for and what to expect

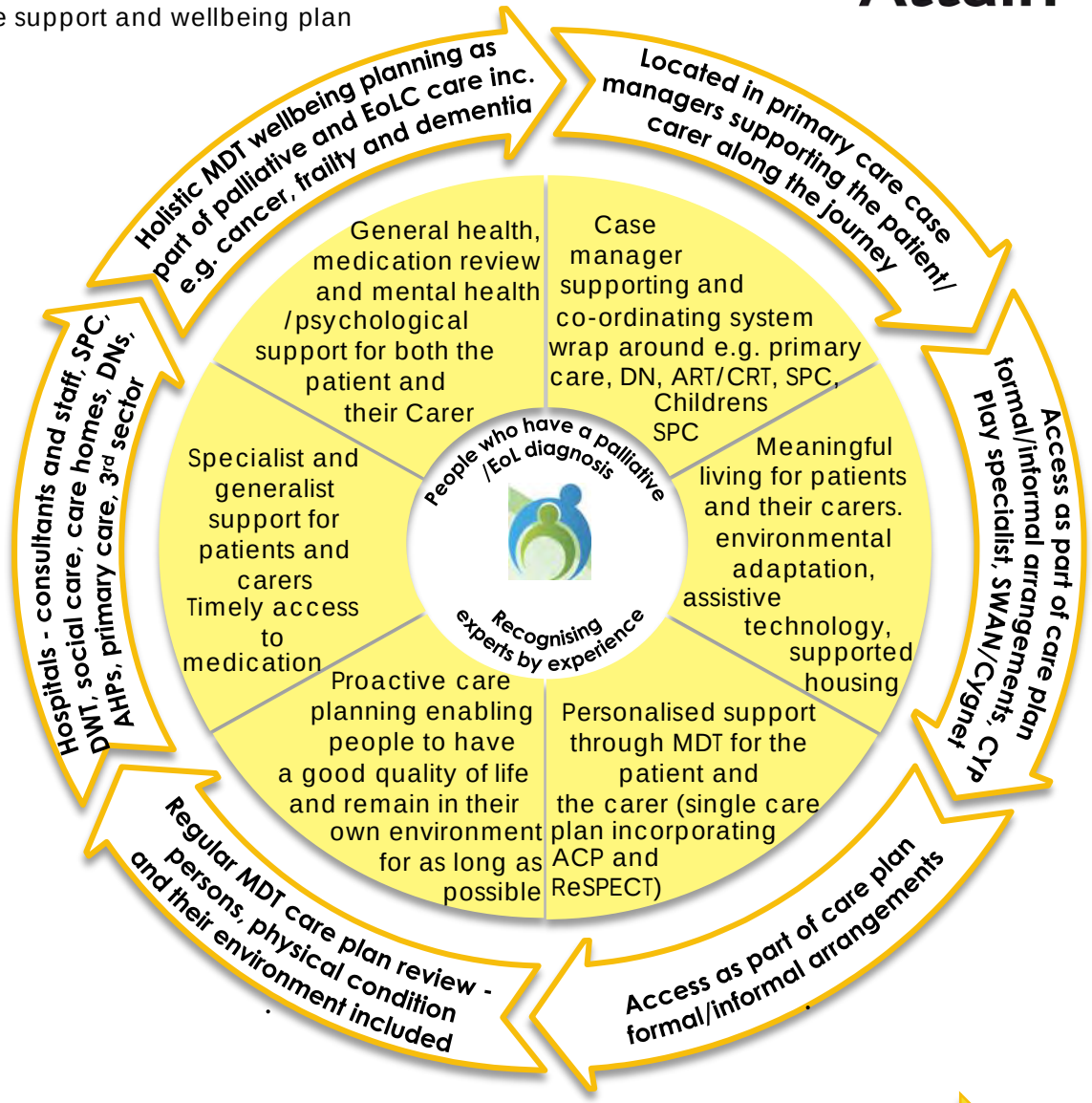



## Living with a palliative/EoL diagnosis

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

- Case manager
- Social care
- Allied health professionals (AHPs)
- District nursing (DN)
- Key workers/ assistive technology lead
- Specialist nurses e.g. admiral, cancer etc.
- Primary care
- Pharmacists
- 3rd sector
- Older Adult mental health
- Advice and training as required from the dementia wellbeing team (DWT)
- Secondary care consultants
- 3rd sector
- **SPC adults/children's**

(N.B. this list is not exhaustive)




Underpinned by training across all staff

# What good looks like for Hywel Dda – The PEOLC service model pathway

The need for increased support in the end days

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

- Case manager
- Secondary care consultants
- SPC adults/children's
- Social care
- 3rd sector
- AHPs
- District nursing (DN)
- Key workers/ assistive technology lead,
- Specialist nurses e.g. admiral, cancer etc.
- Primary care
- Pharmacists
- 3rd sector
- Older Adult mental health
- Advice and training as required from the dementia wellbeing team (DWT)

(N.B. this list is not exhaustive)

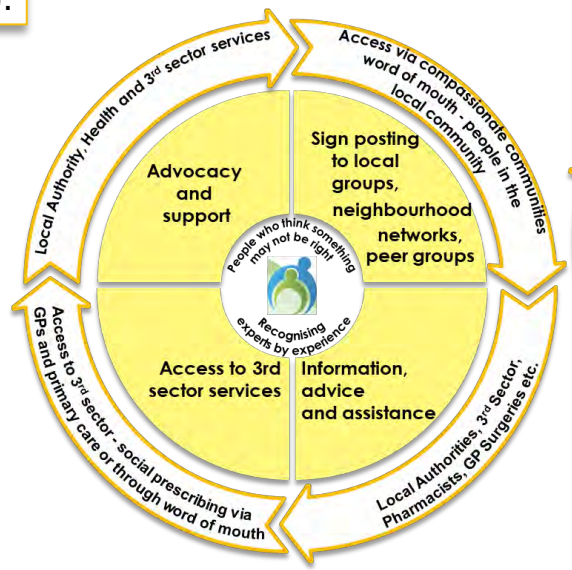
- Implementation of the best practice Scottish Education and Training Framework PEOLC adapted for West Wales - we need to consider the learning and development needs of everyone who is affected in some way by a palliative/EOL diagnosis. This includes patients of all ages, carers, frontline staff, managers, commissioners, regulators, researchers, shopkeepers, next door neighbours etc. Resulting in people who are informed, people who are skilled and people who can provide the right support at the right time

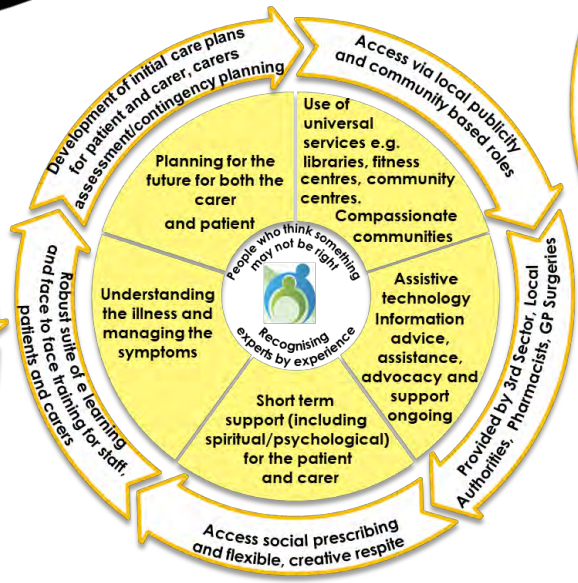

Underpinned by training across all staff

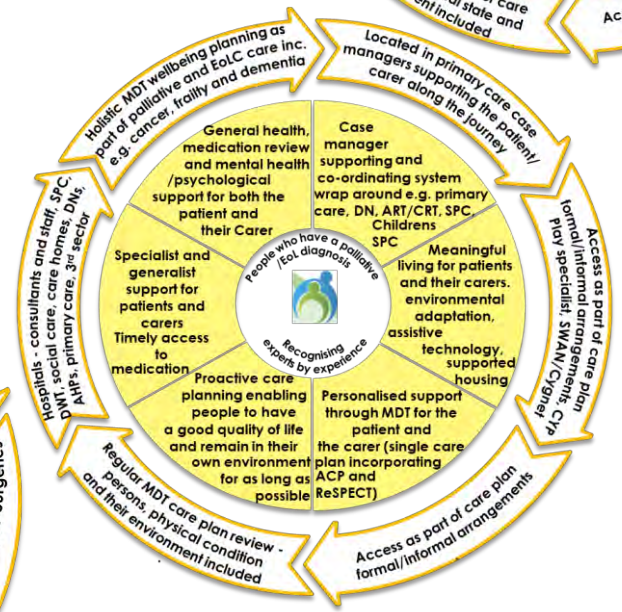
# What good looks like for Hywel Dda – The PEOLC service model pathway

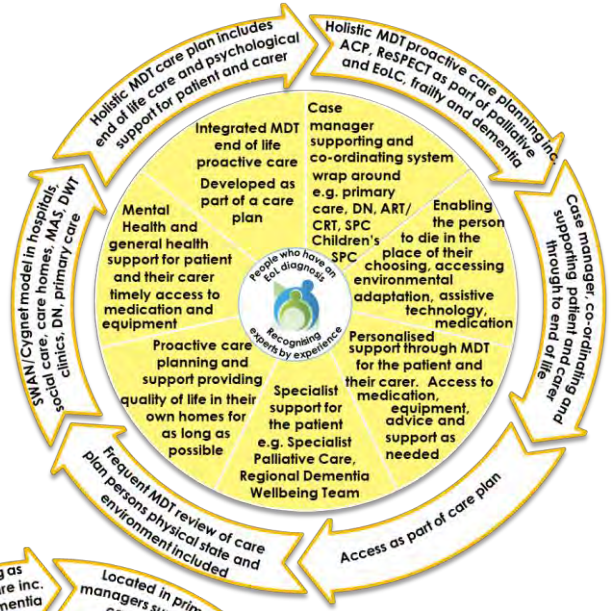
- This draft model, illustrates a new integrated way of providing services. It is based on best practice and existing services within West Wales.
- The service model should be underpinned with an agreed set of service delivery principles which need to be to be developed through the 'All staff are prepared to care' workstream (See section 5).






Underpinned by training across all staff

# West Wales Care Partnership (WWCP)draft dementia strategy and service model pathway

Whilst developing the HDuHB PEOLC strategy, Attain were also commissioned by the WWCP to develop a dementia strategy, vision and service model pathway for West Wales. The draft dementia vision and service model pathway builds on the Attain dementia best practice research report circulated to WWCP Dementia Steering Group in January 2021. The service model pathway has endeavoured to incorporate existing services in West Wales. The service vision and model pathway is in draft form and through further engagement with frontline staff, people living with dementia (PLWD) and their carers, we would expect this model pathway to be further developed. Given that a dementia diagnosis is a palliative diagnosis, the service model pathway converges with the PEOLC service model pathway. Both pathways have similarities e.g. the need for training across all services, a case manager co-ordinator type role, a centralised care plan, MDT way of working with the patient at the centre. For more information please see appendix 3.

# Next steps

Finalising the strategy:

- Seek feedback on the strategy, service vision and model pathway
- Finalise the vision and service model pathway and socialise them so all partners are aware of the direction of travel for PEOLC 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 PEOLC Steering group

Delivering the programme:

- We will develop our programme of work whilst keeping a close eye on the developing NHS Wales National Clinical Framework (NCF); within which, End of Life Care has been afforded National Programme status and the roll out of the Dementia Standards
- Identify resource to set up and manage the programme of work across partners
- We will revise the current programme of work and update the 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
- We will identify additional Workstream SROs to drive work with PMO support, provide ownership and accountability to deliver
- Regular progress updates will continue to be provided at the monthly PEOLC Steering Group

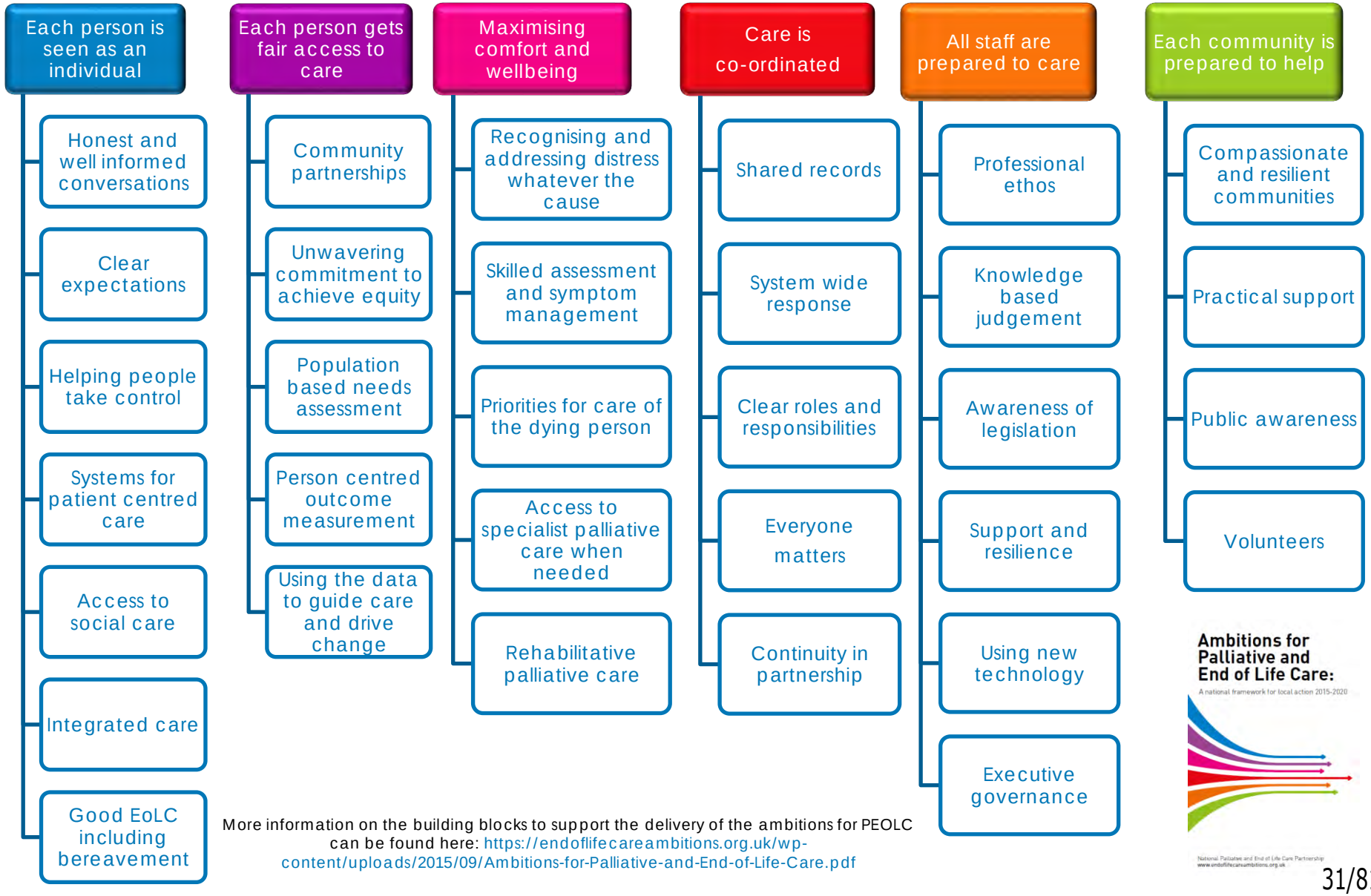
Implementation of the new PEOLC Strategy

# 5. Our approach to implementing the new service model

# Implementing the new service model using the Ambitions for PEOLC National Framework.

Given the West Wales PEOLC principles embraces the Ambitions for PEOLC Framework, it makes sense to align the implementation of the new service model against the 6 ambitions and the 8 building blocks.

It is important to recognise that there is an All Wales SPC service model and team approach to children's services funded centrally and that, while part of the central Welsh team, this service will be built upon locally through the local initiatives outlined in the following recommendations.




More information on the building blocks to support the delivery of the ambitions for PEOLC can be found here: https://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

# Ambition 1

Attain

## Each person is seen as an individual

*I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me.*

*Those who care for me know that and work with me to do what's possible.*

What we are doing and our plans in this area

| | |
|---|---|
| Honest conversations | • We will review the Scottish Training Framework for Palliative Care and consider adopting it across the region. In line with the 2019 NACEL audit, we will develop a training programme stemming from the framework and roll it out across all staff across the region.<br>• We will review and consider adapting and adopting the SWAN/Cygnet model in secondary care and in the community (see appendix 4), and develop a workforce plan to support delivery, which is in line with the Compassionate Cymru approach, across all ages which will provide further training to ensure staff across the system have the skills and confidence to have conversations about death with individuals of all ages and their families and carers. |
| Clear expectations | • We will provide individuals, families and carers with information and will develop an information booklet for carers with information and advice on what to expect at the end of someone's life. |
| Helping people take control<br>Systems for patient centred care<br>Access to social care<br>Integrated (joined up) care | • In line with the 2019 NACEL audit recommendations:<br>  • We will continue to deliver ACP training to health, social care, 3rd sector and care home staff, stressing the importance of involving families and carers in these conversations enabling them to take control over their care plan.<br>  • Following Welsh Government guidelines, we will implement the All Wales Advance and Future Care Planning when it is ready. We will also explore the possibility of adopting the ReSPECT form as part of ACP's (See appendix 5) across health and social care and the development of a Hywel Dda central care plan to share information. |
| Good EOLC including access to bereavement services | • We will review access to bereavement services and address any barriers to ensure fair access for all.<br>• We will consider the outcome of the All Wales bereavement review and implement recommendations. |

# Ambition 2

Each person gets fair access to care

*I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*

What we are doing and our plans in this area

| | |
|---|---|
| Community Partnerships | • We will endeavour to understand where communities may not be accessing PEOLC and any barriers that exist.<br>• We will address inequalities and gaps in services and work with partners to overcome barriers e.g. access to syringe drivers and medication. |
| Unwavering commitment to achieve equity | • Through the relevant workstream, we will review what elements of current adult service delivery (including the role of pharmacists) algin with or are more advanced than the Midhurst Model (See appendix 6) and ensure there is a consistent approach to delivery across the region, including the development of regional standard service operating procedures.<br>• We will address the inconsistent access to community equipment across Hywel Dda for palliative and end of life care patients.<br>• We will ensure a consistent approach to implementing the adapted SWAN/Cygnet model across the region for children and adults.<br>• We will agree a consistent regional approach to identifying those who are at the end of their lives.<br>• We will monitor information to understand where people are dying and if people's preferences are being achieved. |
| Population based needs assessment<br>Person centred outcomes measurement<br>The use of data to drive change | • We have carried out a population needs based assessment and will continue to work towards establishing a HB approach to the collation of data and of person-centred outcomes in line with the all Wales movement to adopt the OACC outcome measures for specialist palliative care. This will be built into our central reporting mechanism process and we will be able to measure person-centred outcomes. We will align our work with the All Wales Children's Specialist Palliative care team to ensure reporting at a central All Wales level.<br>• Building on the best practice research, we will continue to gain insight and work with colleagues to identify and spread best practice on end of life care. |

# Ambition 3

## Maximising comfort and wellbeing

*My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.*

What we are doing and our plans in this area

| | |
|---|---|
| Recognising and addressing distress whatever the cause | • Training delivered to staff and carers will include recognising the signs of distress.<br>• As part of the dementia strategy and service development we will support the development of the recognition tool to aid staff to better support someone with dementia when they present with complex behaviour.<br>• As part of our approach to data collation, we will investigate adapting the NHS Wales Experience Questionnaire for those receiving palliative and EoLC services; this will help us understand if comfort and wellbeing needs (including physical, psychological, emotional and social needs) are being met in secondary care. |
| Symptom management | • In line with the NACEL audit, we will increase training and education in managing symptoms for all staff (particularly for carers and non specialist staff) and also further enhance the work already underway in accessing medications in a timely fashion in both secondary care and the community.<br>• With partners we will develop flexible respite.<br>• We will aim to increase training and education around the use of the Care Decisions Document to support care in the last days of life. |
| Access to services and specialist support | • We will carry out a demand and capacity modelling exercise to clarify patient and workforce need for all SPC provision this will include the modelling of SPC bed demand in secondary care.<br>• To ensure equitable access including access to hospital at home, we will deliver SPC for adults at a regional HB level and consider utilising a similar approach to that of the regional Dementia Wellbeing Team and the All Wales Specialist Palliative and EoLC Team for Children, so that specialists provide training advice and support on symptom management for generalists e.g. care home staff, SALT, therapists, DN's and Social Care staff. Enabling 24/7 access for advice and information for professionals, carers and patients needs to be addressed immediately.<br>• The implementation of the adapted SWAN/Cygnet model will mean the inclusion of a 24/7 advice and support help line for professionals and carers, enabling access to specialist, general and bereavement advice 24/7. The All Wales SPC for Children are also about to roll out a similar service for those working with children across Wales. |

# Ambition 4

## Care is co-ordinated

*I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.*

What we are doing and our plans in this area

| | |
|---|---|
| Shared records | • We will work together to create a shared care plan that is accessible across partners (health, social care and 3rd sector) systems and is owned by the patient and carer. |
| System wide response | • We will work as equal partners with GP practices and primary care, allied health professionals and secondary care, to enable them to understand how they can best support end of life care.<br>• In line with the dementia strategy we will support the mapping of navigator/social prescribing/community connector type roles and develop the business case for case manager/co-ordinator type role for PEOLC, dementia and frailty.<br>• Where appropriate, we will work with our partners to map day service opportunities across the region, identify any gaps and work together to try to address them.<br>• We will develop a consistent approach to the delivery of MDTs across the Hywel Dda region and will support primary care MDTs through, pharmacist, PEOLC representation to provide advice and help to the teams.<br>• The children's SPC team will continue to be part of the All Wales Children's SPC MDT and will share best practice. |
| Clear roles and responsibilities | • The detail and role of the adults' SPC team will be made clear following the mapping of services against the Midhurst model and the subsequent development of a regional SOP for SPC. This will include mapping capacity and the need for different settings to provide PEOLC.<br>• Children's SPC will be enhanced by the adapted SWAN/Cygnet model and a clear SOP will be developed ensuring the lines of accountably, reporting and interface with the All Wales Children's SPC service. |
| Everyone matters | • SOP development for children transitioning into adult services will improve co-ordination of care.<br>• SOP development for the adult SPC service will improve the co-ordination of those with chronic conditions including those living with dementia and learning disability. |
| Continuity in partnership | • We will work wherever possible to create a palliative and EoLC service offer that is consistent across the region.<br>• We will work together across the system reviewing our processes to ensure people receive joined up services. |

# Ambition 5

Attain

## All staff are prepared to care

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

What we are doing and our plans in this area

| | |
|---|---|
| Professional ethos<br>Knowledge based judgement<br>Awareness of legislation | • All staff across health, social care and 3rd sector use an holistic, person-centred approach to assessments, care planning and reviews. The needs of the carer will be considered at each step of the way.<br>• The Health Board will commit to supporting both children and adult SPC services having protected time to deliver education and will work with colleagues in primary and secondary care to support the release of generalist staff to attend such training.<br>• The new Adult SPC and Children's SPC teams SOPs will include the requirement for staff to help train generalist staff in the community and secondary care in relation to some of the more complex elements of palliative care thereby enabling the delivery of high quality palliative and EoLC. |
| Support and resilience | • Through the adoption and implementation of the Scottish Training Framework for Palliative Care, all staff will receive formal training on EoLC legislation and the Mental Capacity Act 2005. Formal palliative and EoLC training will include training on difficult conversations, negotiation and overall resilience.<br>• Teams will be required to keep a training log capturing a record of those trained. |
| Using new technology | • We will build on the use of technology in the phase one report e.g. virtual/remote assessments and consultations, remote monitoring of patients and are reviewing where more specialist roles may be needed. These need to be developed with local providers but could include specialist roles in end of life care for people with learning disabilities. |
| Executive governance | • In line with the NACEL audit recommendations, HDuHB have approved the recruitment of a clinical lead to work as part of a triumvirate team to oversee the implementation of the new strategy through regional pooled budgets.<br>• The Heath board should appoint a named pharmacist to support improvement of medicine management for seriously ill and dying patients in line with the Welsh Government and NHS Wales, 2017, Palliative and End of Life Care Delivery Plan. |

# Ambition 6

Attain

## Each community is prepared to help

*Death and dying are inevitable. Palliative and end of life care must be a priority. The quality and accessibility for this care will affect all of us and it must be made consistently better for all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes.*

What we are doing and our plans in this area

| | |
|---|---|
| Compassionate and resilient communities<br>Volunteering | • We will be active in supporting the https://compassionate.cymru/ Charter and the Welsh Government's ambitious project to make Wales the world's first Compassionate Country and at neighbourhood and at street level we will form flexible teams which make the most of medical and formal social care input by identifying and enabling community support in ways which genuinely address the question, **'What matters most to you?'** This will enable the adapted SWAN/cygnet model roll out at neighbourhood level. |
| Practical support | • We will support the compassionate communities initiative and explore implementing Compassionate Cymru across Hywel Dda and we will join up our services wherever possible to maximise resources and reduce duplication of effort.<br>• As identified in our stakeholder workshops, there is a need to start conversations about death and dying earlier. We will explore with partners what we can do to best support teachers and staff working in children and young peoples' services to start conversations with children and young people. |
| Public awareness | • We will raise public awareness about death and dying, one way will be through Dying Matters Awareness Week – focusing on the importance of being #InAGoodPlace to die. https://www.dyingmatters.org/ |

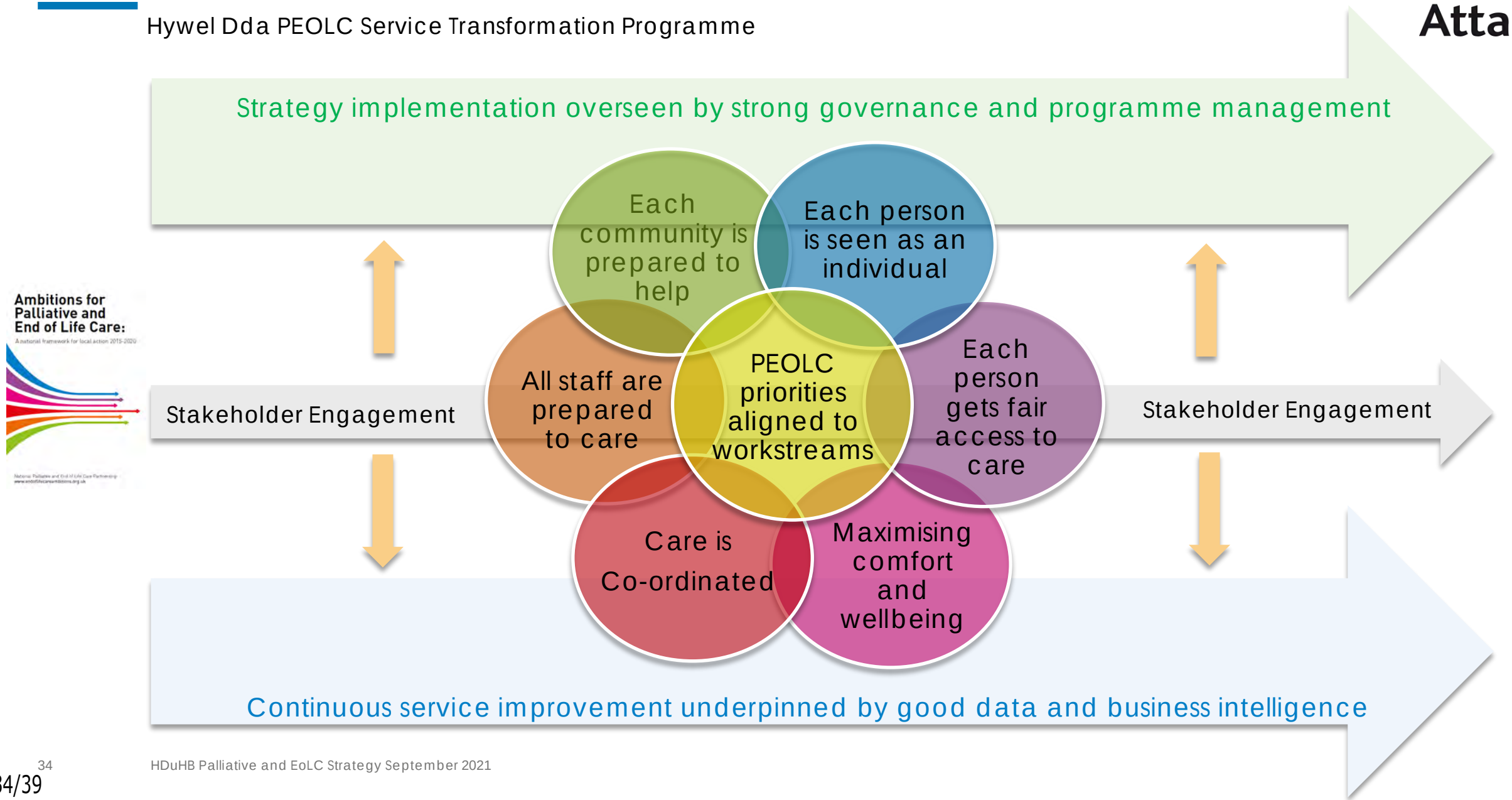
# Delivering the strategy ambitions through programme management

Building on the new PEOLC programme approach, implemented following the key outcomes from the discovery phase, this next phase of work in relation to PEOLC will take place over a 5 year period with integrated service transformation and continuous improvement, utilising a key workstream and deep stakeholder engagement approach.

Alongside this work, the regional dementia strategy will be further co-designed with frontline staff, people living with dementia and their carers, a programme of work will also be developed and similar to the PEOLC strategy once the dementia strategy is signed off by all partners a regional programme will be developed in order to implement the recommendations.

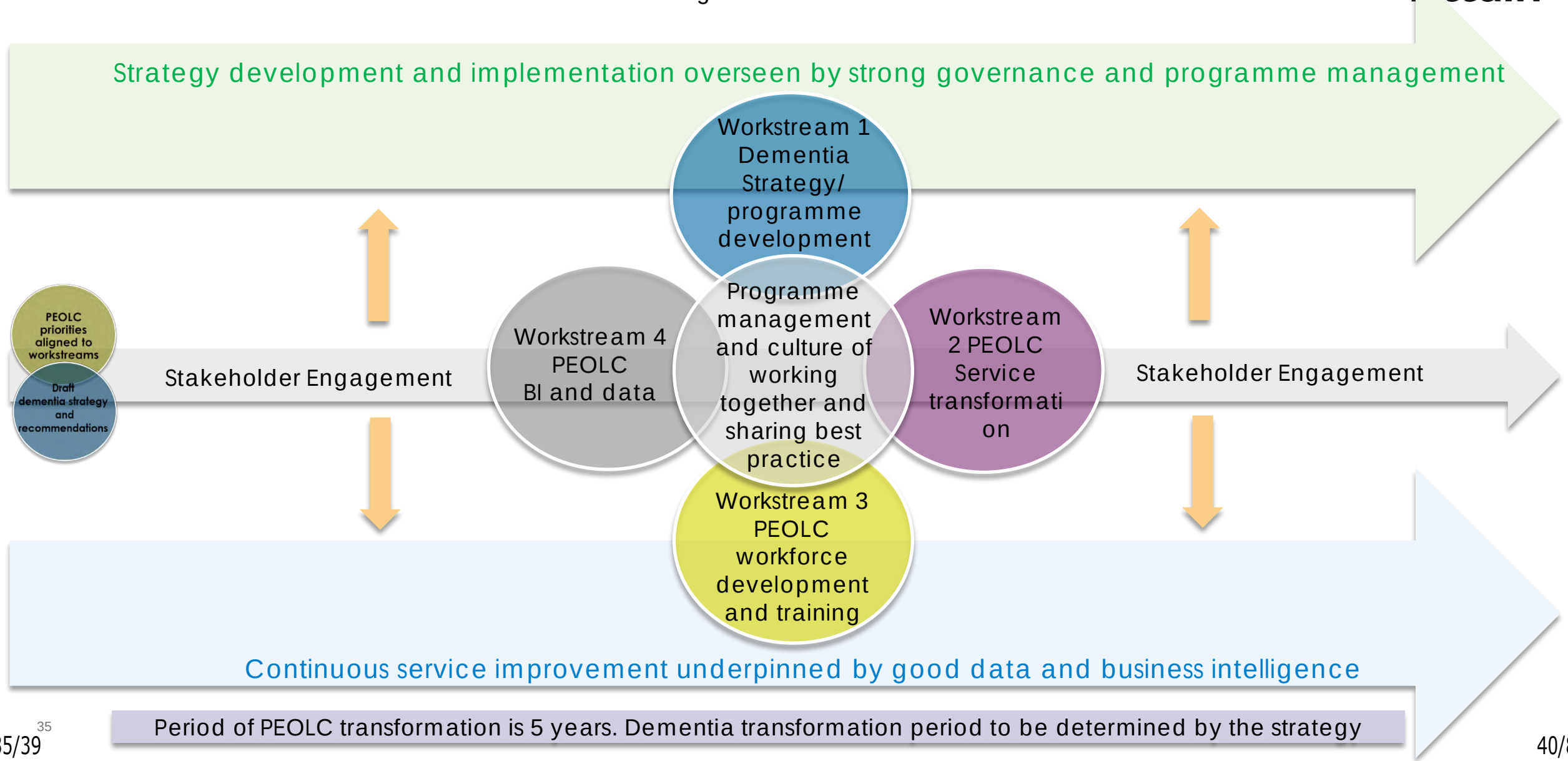
# Approach to implementing the PEOLC strategy ambitions and new model of care

Hywel Dda PEOLC Service Transformation Programme



# Proposed workstreams to deliver the PEOLC strategy and development of the dementia strategy and programme

PEOLC and Dementia Service Transformation Programme

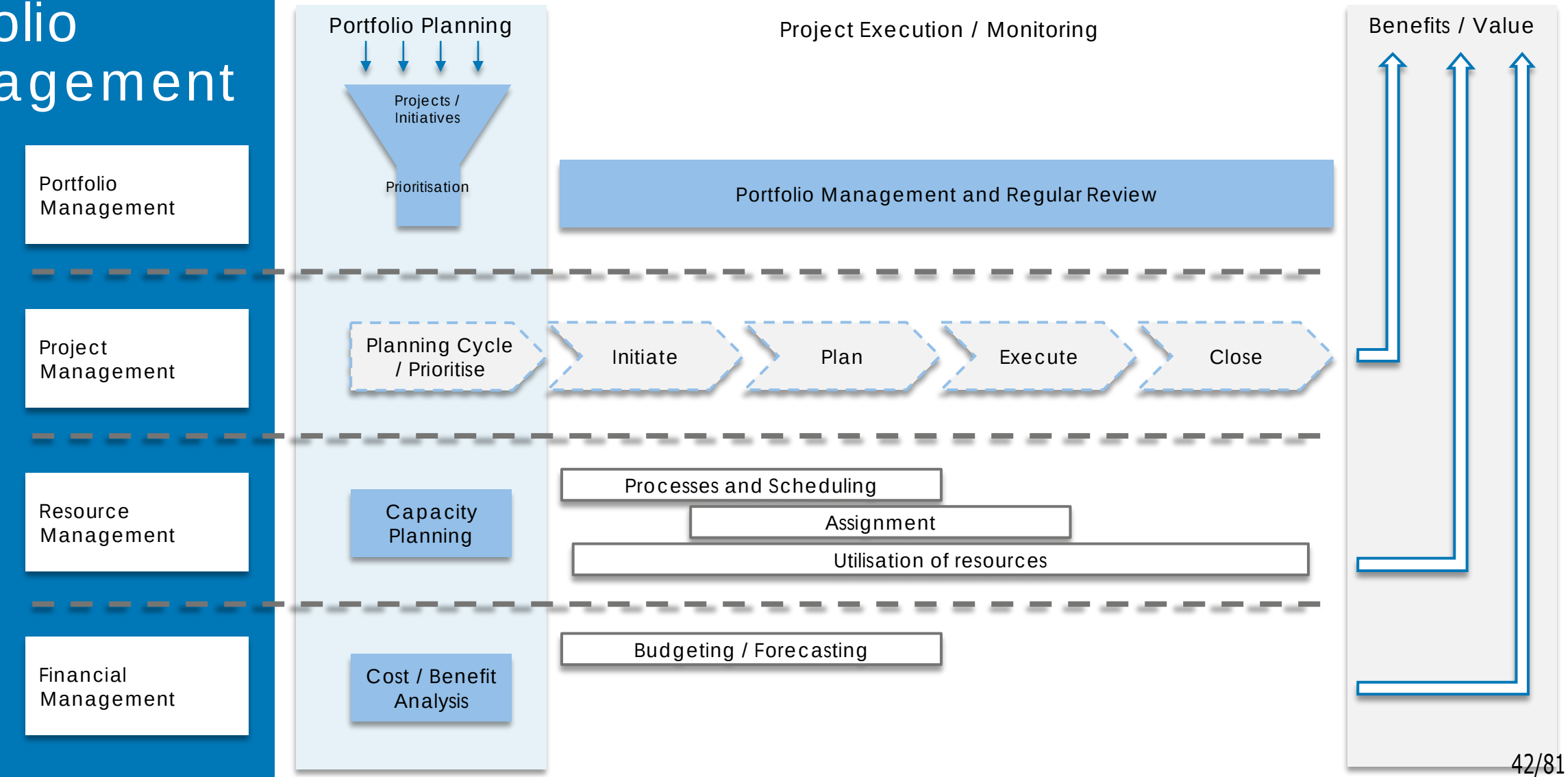


# Proposed Delivery Approach: Portfolio Management

The below indicative set of portfolios will provide structure to deliver the next phase of work developing the dementia strategy/programme plan as well as achieving the transformation in PEOLC services in Hywel Dda. The PEOLC priorities are in line with the Ambitions for Palliative and EoLC National Framework, the 2019 NACEL audit and builds on the initial continuous improvement programme. Any outstanding work from the continuous improvement programme will be merged with the appropriate workstream within this new programme of work. The dementia priorities will be overseen by an SRO along with the WWCP dementia steering group. The PEOLC priorities will be overseen by the triumvirate within the Health Board PEOLC steering group and each portfolio will be led by an SRO from across the system. However, the whole programme of work will also be overseen by the WWCP. Resources will need to be idenfied over the life of the programme to enable continuation of service delivery whilst frontline staff work to design and develop the services.

| | Dementia strategy, programme plan development and continuous service improvement | PEOLC transformation | Workforce development and training | BI and data |
|---|---|---|---|---|
| Aim | A co-designed regional dementia strategy fully singed up to by the WWCP. Robust achievable implementation plans. | Implement priorities stemming from the PEOLC strategy that relate to achieving each person gets fair access to care. | Implement priorities stemming from the PEOLC strategy that relate to achieving maximising comfort and wellbeing. | Implement priorities stemming from the PEOLC strategy that relate to a uniformed approach to collection business intelligence and outcomes. |
| Priority Areas | • Map navigator, social prescribing and community connector type roles and develop the business case for dementia case co-ordinator role.<br>• Co-designed regional dementia strategy, vision and service model pathway – phase 2.<br>• Regional programme plan developed to deliver the strategy recommendations.<br>• Initial regional dementia programme plan developed to deliver continuous service improvement while the strategy is being further co-designed and signed off.<br>• Frailty priorities and deliverables to be agreed within the resource available. | • SPC service mapping and development of a new regional SPC service including a transition SOP between Children's and Adults' services. The use of technology will be built into the new service.<br>• Development of PEOLC model for the region with supporting business case, using the best practice principles from the SWAN and Midhurst models.<br>• Development of bereavement services in line with the All Wales Bereavement framework.<br>• Implementation of the PEOLC strategy recommendations in relation to service transformation. | • Adaptation of the Scottish Palliative and EoLC training framework and development of implementation plan<br>• Development of a workforce plan to support service transformation delivery<br>• Continuation of ACP training<br>• Implementation of the All Wales Advance and Future Care Planning when ready and development of a central care plan (across frailty, dementia and PEOLC<br>• Support the development of the dementia recognition tool<br>• Implementation of the PEOLC strategy recommendations in relation to workforce development and training. | • Population needs, workforce and demand and capacity modelling for new regional SPC with supporting business case.<br>• Data driving change – development of a reporting dashboard and development of a new job description for an analytics role for frailty, dementia and PEOLC.<br>• Implementation of the PEOLC strategy recommendations in relation to BI and data. |

# Proposed Delivery Approach: Portfolio Management



# Next steps

Finalising the strategy:

- Seek feedback on the strategy, service vision and model pathway
- Finalise the vision and service model pathway and socialise them so all partners are aware of the direction of travel for PEOLC 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 PEOLC Steering group

Delivering the programme:

- We will develop our programme of work whilst keeping a close eye on the developing NHS Wales National Clinical Framework (NCF); within which, End of Life Care has been afforded National Programme status and the roll out of the Dementia Standards
- Identify resource to set up and manage the programme of work across partners
- We will revise the current programme of work and update the 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
- We will identify additional Workstream SROs to drive work with PMO support, provide ownership and accountability to deliver
- Regular progress updates will continue to be provided at the monthly PEOLC Steering Group

Implementation of the new PEOLC Strategy

# Contacts

| | | |
|---|---|---|
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# Hywel Dda University Health Board (HDuHB) Palliative and End of Life Care (EoLC) Strategy - Appendices

Attain
Improving health and wellbeing

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Hywel Dda University Health Board

September 2021 v2.1

These appendices should be read in in conjunction with the main strategy v2.1, Attain EOLC best practice examples report published February 2021 and the HDuHB palliative care discovery final report v2.7 published May 2021

**'To provide excellent palliative and end of life care across West Wales enabling people to be cared for and die in their preferred place of care'**

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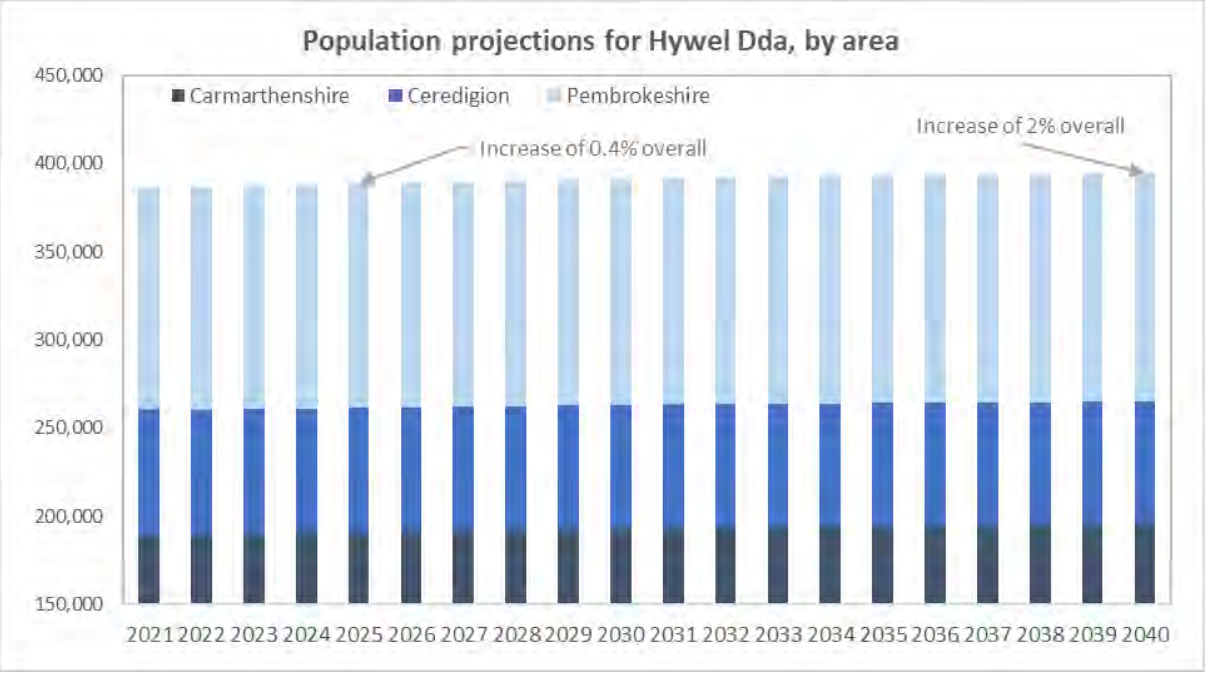
# 6. Appendix 1: Population needs analysis summary

# Hywel Dda population analysis (ONS)

Overall the population of Hywel Dda 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

# The impact of aging population on care

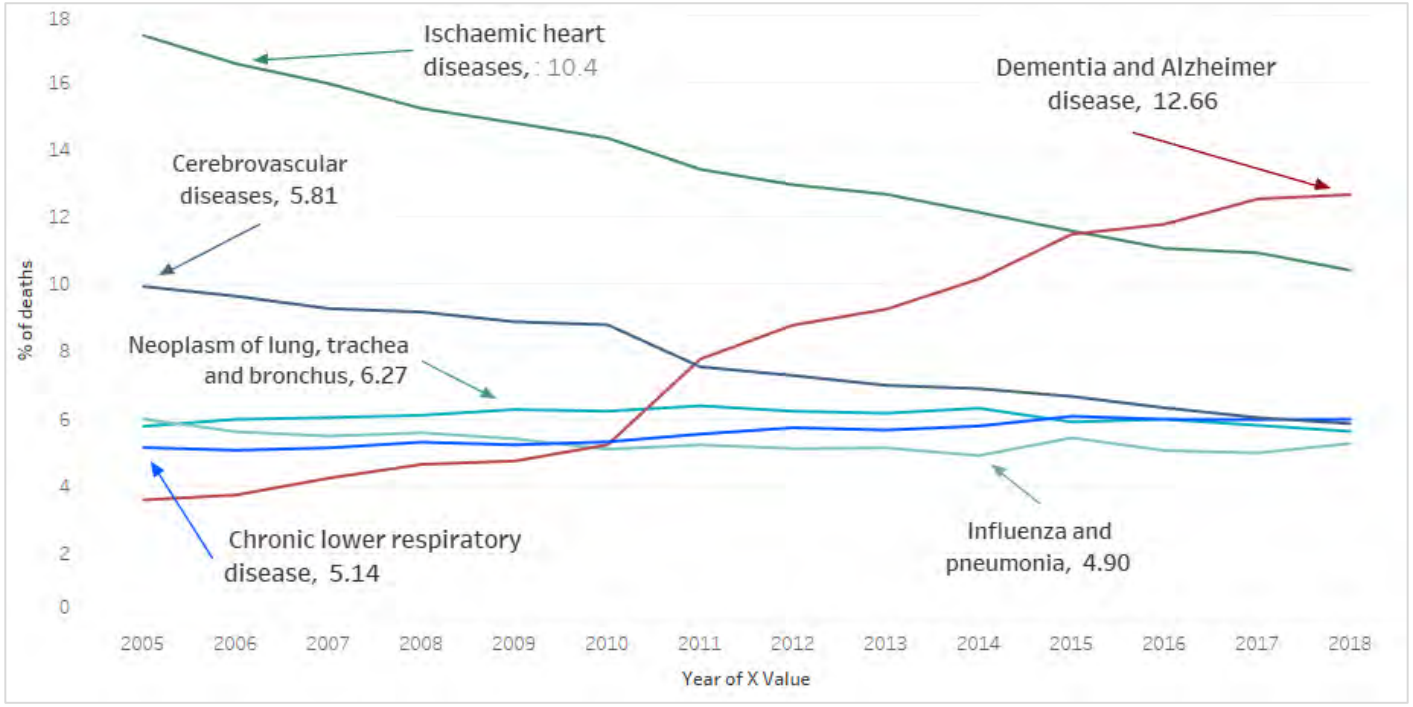
It is estimated that over 58% of people over the age of 60 have two or more long term conditions to manage. In Wales, over 3% of the population have CHD. According to the British Heart Foundation (BHF) around 3,600 people per year die of a coronary heart condition with two thirds of them being over 75 years old.

On GP registers in Hywel Dda (18/19) there were nearly 4,800 people with heart failure and over 14,000 with a diagnosis, at some stage, of cancer (3.5% of registered population). Further, there are over 9,000 people on the register with COPD. It is likely that a large portion of these people overlap, given that we know that people become increasingly co-morbid as they age.

The leading cause of death (pre-COVID-19) in the UK is dementia with 12.7% of deaths registered being related to the condition. With over a third of the Hywel Dda population expected to be over 65 by 2024, and with over 10% of the total population set to be over 80, it is likely that the pressures on palliative care will become more significant.

People are living longer, and people with terminal illnesses are therefore living with complex needs in addition to their terminal illness.

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



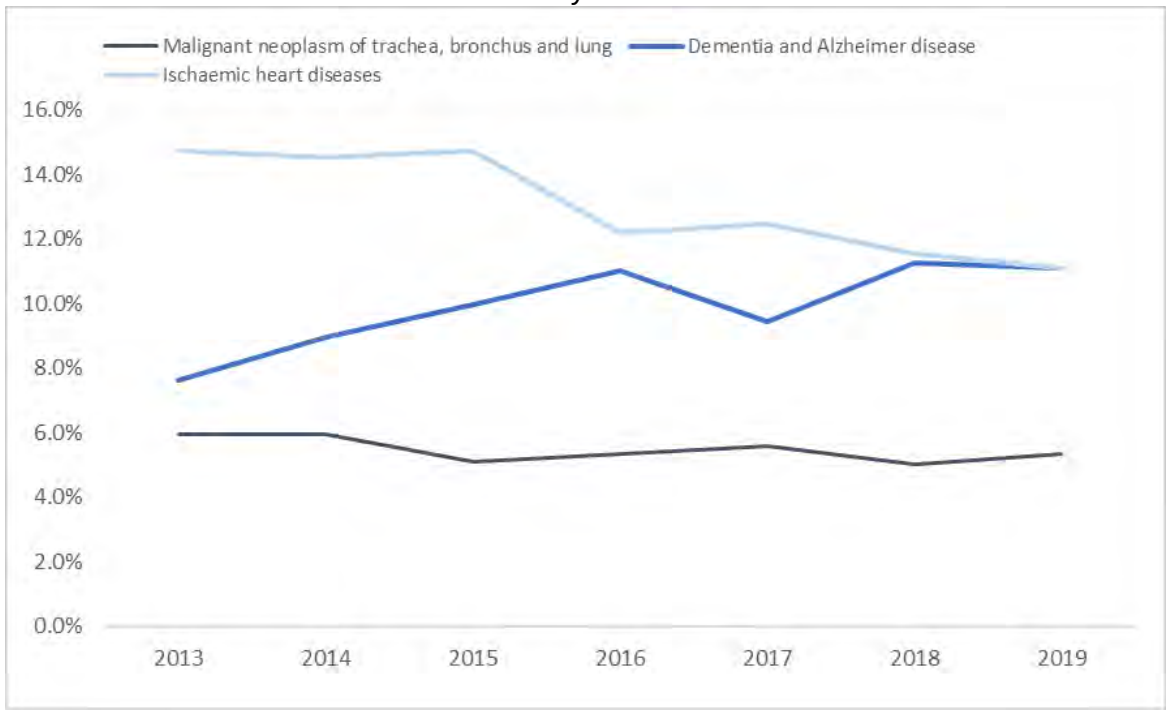

Sources: dementia statistics and Wales QOF publications

# Mortality by cause Hywel Dda

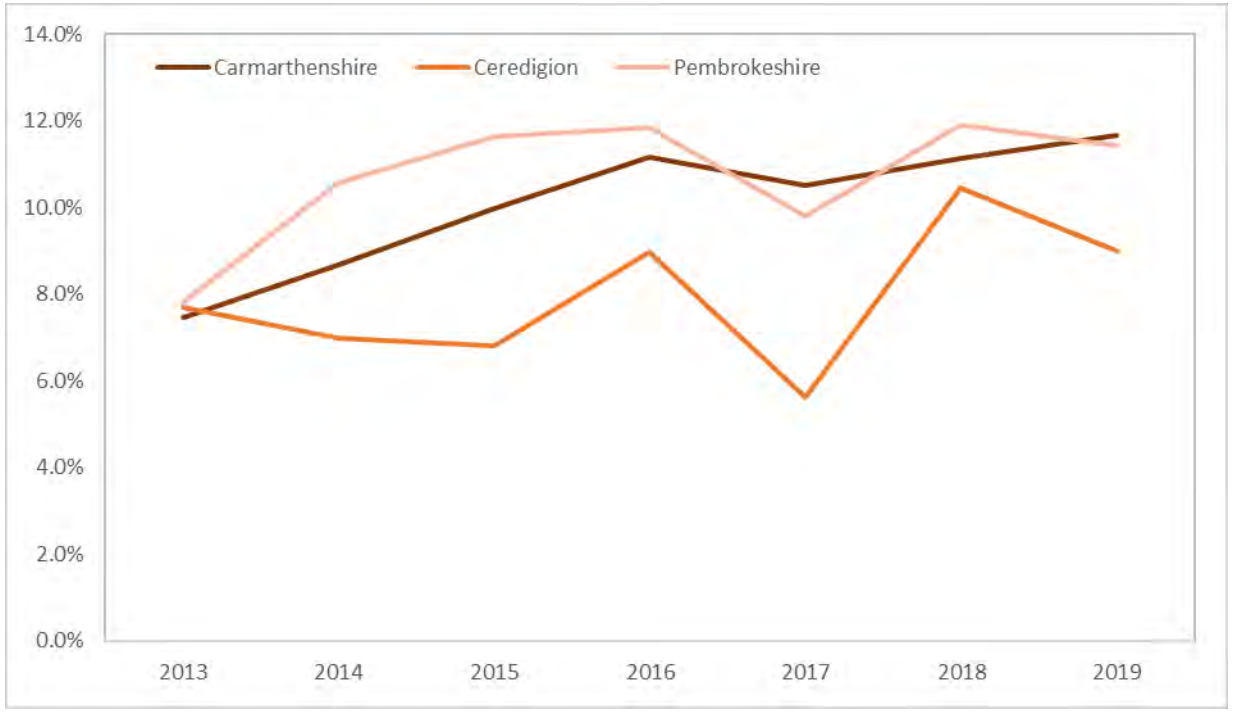
There is a similar pattern across Hywel Dda as there is across the UK for main disease type cause of death. As can be seen below. IHD and Dementia have converged over time, with IHD declining consistently and dementia increasing over the same period.

Lung cancer has remained fairly stable as a main cause of death, declining slightly as a proportion. The below also spits out dementia as the fastest growing cause of death, with quite a lot of variability in Ceredigion (with younger population overall and fewer deaths, due to small population) with both Carmarthenshire and Pembrokeshire increasing from under 8% in 2013 to over 11% in 2019. Specific diagnoses of Stroke were considered but individually none make up more than 3%. Combined; all Cerebrovascular disease represents less than 6% of deaths across Hywel Dda and remain fairly stable across time

Mortality by disease type: IHD, Dementia and Lung cancers year on year for Hywel Dda




Mortality due to dementia by county over time as a proportion of total deaths



# Mortality and palliative care

From the All Wales PEOLC Delivery Plan 2017, it is estimated that 0.75% of the Welsh population have palliative care needs at a given time. Applied to the population of Hywel Dda this equates to roughly 2,900 people.

"The report suggests an estimated prevalence rate for children and young people likely to require palliative care services as 15 per 10,000 population aged 0–19" this equates to 12-13 children in Hywel Dda.

The below data was taken from ONS and gives the number of deaths within each county by age groupings.

Mortality by age group 2019 (Note, CYP will be an over estimate) from ONS

| Age group | All Wales | Carmarthenshire | Ceredigion | Pembrokeshire | Hywel Dda |
|---|---|---|---|---|---|
| CYP (0-19)* | 198 | 6 | 0 | 11 | 17 |
| Adult (20-64) | 4,979 | 304 | 113 | 181 | 598 |
| Older People (65+) | 28,006 | 1,898 | 668 | 1,333 | 3,899 |
| Total deaths 2019 | 33,183 | 2,208 | 781 | 1,525 | 4,514 |

Using the above assumption this means that of the circa 4,500 deaths across Hywel Dda potentially more than 65% of those people, at one point or another, required some form of end of life care services.

"By 2040 … If age and sex-specific proportions with palliative care needs remain the same as in 2014, the number of people requiring palliative care will grow by 25.0% … However, if the upward trend observed from 2006 to 2014 continues, the increase will be of 42.4%" **

* CYP data: Numbers are very low and in cases where the 5 year age grouping was below 5 numbers were supressed and automatically rounded up to 5. This means that this number is likely a slight over estimation of deaths for 0-19 year olds

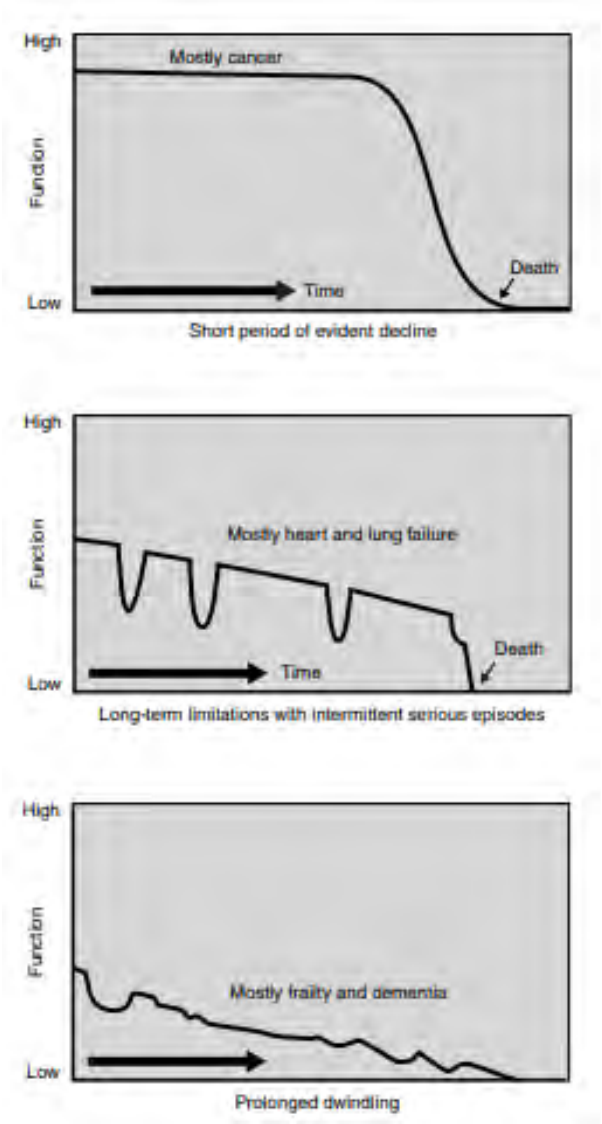
** How many people will need palliative care in 2040? Past trends, future projections and implications for services - S. N. Etkind et al

# Cohort model*

The table to the right is often used to help understand the trajectories of people's illness. Particularly as it pertains to their death.

With the ageing population and reducing adult age population, there is a risk that there may be less people to provide the care or carers roles for those aging complex patients with the need for greater levels of care

If 42% of the deaths in West Wales require a longer term, more active care plan in the period leading to the person's death, then this will result in a potentially different workforce requirement.




| Trajectory | Characteristics of the last year of life | Number of deaths (>18) in England* |
|---|---|---|
| Sudden death | Any deaths where there was no obvious prognosis until last days | 14% |
| Cancers | Gradual decline and then rapid end stages but without previous exacerbations or sudden changes in need. | 21% |
| Other terminal | Gradual decline with some exacerbations in initial phase of last year then rapid end stage | 4% |
| Organ failure | One predominant chronic condition with regular or fairly frequent exacerbations and with end of life typically being the result of a crisis and therefore more rapid deterioration in functions. | 19% |
| Frailty | Multiple co-morbidities accumulating with increasing age leading to a gradual decline and regular exacerbations before last days. | 42% |

* This well recognised and widely accepted cohort model has been adapted and used across the world including studies in Australia and the USA, the above is illustrative and we continue to search for an applied Welsh version.

Source: 'Living Well at the End of Life' by RAND Health and 'Illness trajectories and palliative care' by Scott A Murray et el

# 7. Appendix 2: Key themes identified from stakeholder engagement

# Emerging Themes from the workshops held in May 2021

- Access to quality End of Life care varies across the system
- There is a need to join-up services across the whole system, including within and across sectors
- **This is everybody's business**
- Obstacles and barriers make it difficult for professionals to have End of Life conversations; a cultural shift is required to have meaningful conversations
- Third sector support is vital, examples of good practice should be shared and scaled across Hywel Dda
- Training is essential and there are gaps in current provision; staff need to be trained adequately
- Ongoing support should be available for care home staff and wider professional groups regarding the emotional impact of work
- Lack of timely supply and removal of equipment in peoples homes (not in Pembrokeshire)
- No shared IT systems to transfer information in a timely way; Digital Maturity is quite low
- People often end up with many care plans from different professionals; a single care plan would be a significant improvement
- Wider holistic needs should be assessed and supported through a central care plan that the ACP/RePSCT from is part of
- Timing conversations can be difficult
- Building trusted relationships is vital
- Big challenges to obtaining medications at home leading to unnecessary pain and discomfort
- Communication between providers in different sectors, and between providers and patients could be improved
- Roles and responsibilities across the pathway are not always clear; a single coordinator role would be very useful
- There is a desire to breakdown barriers to improve provision across the system
- Access to 24/7 advice and support for professionals and carers is needed

# The opportunities and challenges presented by the best practice models for HDuHB - outputs from the 17/05/21HDuHB workshop attendees

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## Midhurst MacMillan Model of Community Based Palliative Care

### Opportunities

- We want the component and features of the Midhurst model
- This model enhances what we are already doing
- ART and CRT are already carrying out some of the services that the Midhurst model provides we could expand on this
- Model similar to Ceredigion – opportunity to build on this model across the regional footprint – equitable services
- We could identify the roles that are needed and how they connect
- Single PoC approach – could tie in with the clinical streaming hub from UPC and the SPoC being developed in house
- A single number for all to call would make a huge difference
- Opportunity to develop 7 days working in conjunction with SPoC – currently CNS doing on call have days off in week (loss of 2 days) – will need additional funding
- Shared electronic records – various professionals can access various systems – create a consistent joined up approach
- Joined up approach which could be built using our current fragmented services
- Slicker systems – e-prescribing, referrals etc - ties in with national programs

### Challenges

- Poor referral practices to SPoC could be addressed by simplicity of connection
- Many partners will need to be involved – currently some of the services are delivered by third sector via SLAs
- 7/7 working appropriate support around including over night
- Small population but seems an expensive model with low referrals - ? Value for money
- Doesn't seem new or innovative – hard sell
- Was it a full MDT model – not all part of the team i.e. Pharmacy and Therapies

These opportunities and challenges have been taken into account in the designing of the service model and recommendations within this strategy

# The opportunities and challenges presented by the best practice models for HDuHB - outputs from the 17/05/21HDuHB workshop attendees

## SWAN and Cygnet Model of End of Live Care

### Opportunities

- We want the components and features of the Swan model in HD
- 'Everything we should be doing'
- Bottom up – it becomes everyone's business – demonstrates compassionate care
- Whole system approach – can be very efficient – drives out inefficiencies and savings will follow – ties in with value based healthcare approach
- We set the tone of what we want the response to be in non-specialist settings e.g. wards
- Little things can have big impact – simple quick wins we can implement now – mandatory training (been asked for, for many years), Datix good practice (+ve culture)
- Opportunity to work with acute colleagues – gives us an 'in'
- Releases specialist palliative care resource to deal with the complex – generalist palliative care is truly everyone's business then
- Training for non-registered staff
- This is a way of making palliative and EoLC everybody's business e.g. like safeguarding currently is

### Challenges

- Currently 'no one's' business – cultural change on a grand scale
- Pressures on acute hospitals to discharge – how can we overcome this and get acute buy in?
- Needs considerable manpower to front load it and roll out
- Challenge of staffing and continuing nursing on the ward
- Needs dedicated nurses for the hospitals
- We haven't thought enough about all who die
- The boundaries we create are what restricts us
- Recognition at Board level
- There is little funding in regard to bereavement services

These opportunities and challenges have been taken into account in the designing of the service model and recommendations within this strategy

# Highlights of what we are doing well

The PEOLC staff overall are very experienced, committed and are looking forward to the chance to improve their services. This is what patients and carers had to say:

The social worker we had was brilliant and we built a great rapport

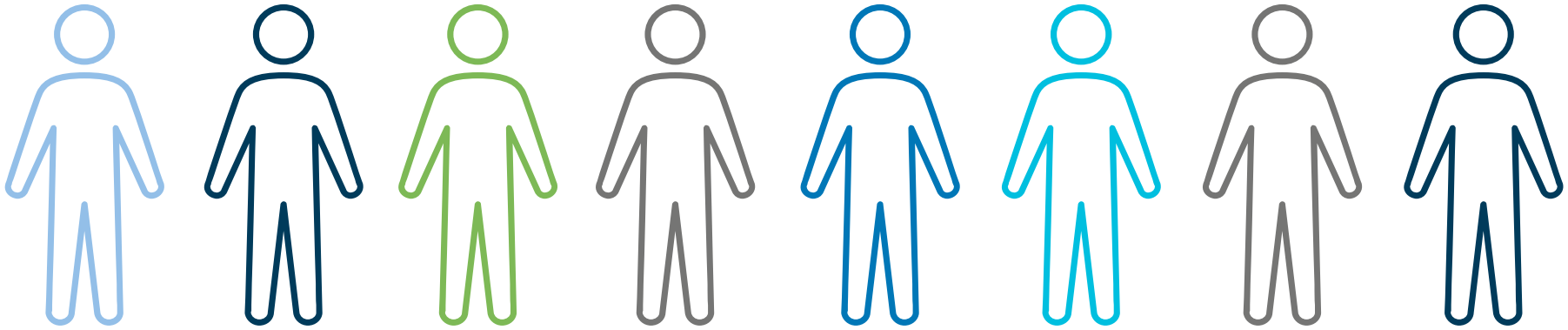
The services were brilliant, all great. We were supplied with pretty good information from the hospital, palliative care and district nurses.

Our local play specialist is brilliant. At the beginning of COVID our play therapist went above and beyond organising food parcels – it was nice to know we had enough food – we couldn't get a delivery slot

Specialist nurses have **been brilliant don't know** what I would do without them. Good palliative nurse from the surgery came every week towards the end DNs were fantastic - everyone worked together

**Can't fault the treatment** I've received, the nurses have been fantastic. Mum had a good death we were cared for and not forgotten always used my first name.

The out of hours Dr was very good and most supportive gave me strategies to keep going



The themes stemming from over 15 interviews held in phase 1 with patients and carers have continued to influence the service vision, model and recommendations within this strategy.

| Access to Medication | Being Listened To | Getting Timely Diagnosis/Treatment | Joined Up Services | Support for Carers |
|---|---|---|---|---|
| Medication access was stressful due to having to collect drugs from Chemist (Nurses can't carry the required meds) | Some patients feel that they are not listened to by GPs and some health professionals only seeing them as a diagnosis | There are examples of patients and carers having to repeatedly push their GP to be referred to specialist delaying timely diagnosis | It shouldn't be a post code lottery, primary care doesn't necessarily need to be GP led | Mental health support 6 sessions - not enough and having a session every week doesn't fit in with patients/carers needs |
| Palliative care nurses invaluable in sorting out syringe drivers and would be good if they could prescribe | There are examples of patients struggling to receive treatment for things unrelated to their diagnosis | Patients travelling long distances and some having to go directly to A&E in the absence of access to a GP | Why do I have to keep repeating what meds I am on - why can't they look it up and ask if anything has changed? This is very tiring for me | So many meds with certain times to be taken - you have to learn very quickly what medicine does what. CNS help train carers to administer |
| Many carers expressed their anxiety and stress around accessing medications with some building in a 5 day lea way | Some people have had to push for the services and equipment such as specialist beds (not relating to Pembs) | Palliative CNS and 3rd sector services have enabled access to equipment, medication | Mental health support has been non existent - doesn't fit with what people need | Continuity of care is invaluable. CNS, play specialist, social care and 3rd sector services highly praised by some |
| Meds only prescribed in hospital causes stress on the carer to fight for the medications to be prescribed in the community | One of the main obstacles to achieving transformation is that services work in different ways across the region | Some patients feel they have slipped the system with second diagnosis getting picked up too late | 3 consultants - all on the same system why can't they share my records? Services don't join things up | Some carers wondered how people access the care / information they need when they don't know the system |

# The themes stemming from the interviews with stakeholders in phase 1 have continued to influence the service vision, model and recommendations within this strategy.

| Strategy and Leadership | Budgets and Funding | Workforce and Training | Principles | Governance |
|---|---|---|---|---|
| A clear (PEOLC) strategy is needed with an agreed service model across the region which would address the disparity in the level of provision | Absence of long-term funding is a challenge to service development Charities are experiencing reduction in charity revenue due Covid-19 | Need to review workforce skill mix / levels and alignment. High staff turnover in some areas and struggles with recruitment | Single point of access / referral is required to manage demand. Varying view as to the priority given to palliative care services | Needs to be clear priorities communicated to the Health Board by the Welsh Government |
| The profile of specialist palliative care is now a top priority for the Health Board with an executive lead | HB community and primary care services have paid for a lot of Advance Care Planning | New ways of working need to be established to maximise Consultants time. Need a lead CNS nurse for Palliative and EoL care | Community Health Services often don't know anything about a patient until patient is waiting to be discharged from hospital | Need to become one organisation across NHS and Local Authority |
| Need to look at how services can work better across specialisms. Conflict between what is a general role vs dedicated palliative care | Difficulties in getting packages of care, balancing NHS/ independent contributions within care packages needs to be proportionate | Redeployed inpatient SPC team staff have positive experience working with acute response team | Limited access to psychology support for families and children | Capacity (caseload) management systems seem to be ad hoc |
| Need clinical, managerial and project resource to support the Executive Leader | Absence core funding for adult bereavement counselling services | Need a lead CNS for Palliative Care and EoL care who can also cover clinical duties | Requirement to have EoL conversations earlier. Some professionals reluctant to enter in ACP conversations | Need to ensure clarity around DNAR thresholds conflicting and varying Covid-19 guidance |

# The themes stemming from the interviews with stakeholders in phase 1 have continued to influence the service vision, model and recommendations within this strategy.

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| Operational Procedures | | Data and Technology | Commissioning | |
|---|---|---|---|---|
| Good examples of MDT working across the region but this is not consistent across all service areas | A lot of ACP expertise resides within the charitable organisations Large amount of time liaising with Oncology in Swansea | Encouraged to adopt remote technology e.g. *Attend anywhere*. Some access via portal to GP systems and information | There is a need for a clear palliative and EOLC care strategy and for an agreed set of standards, outcomes and metrics for services to report on at HB | 3rd sector services have been commissioned in a ad hoc way and there is disparity across the region |
| There needs to be more seamless (integrated) care across day services and Out-of-Hours | Need for improved communication between District Nurses and Marie Curie team | Information is held outside clinical systems / PAS Need an integrated system such as SystmOne | Develop a culture across all settings where PELOC embedded in everything we do - a core business and speciality available when needed | There are no standard operating procedures in place |
| Need to maximise skill mix between ART/CRT and palliative care CNS e.g. Positive experiences in Carmarthen during COVID-19 | Acute team not always aware of resources to help or the pathway to support patients at home | Access to reliable data is the main barrier to achieving transformation | How do we change culture to get consistency in provision in order to measure population outcomes? | There is a need for a single HB team- managing budgets, delivering the services together, people populations getting their needs met |
| More can be done in primary care to stratify the population and identify those requiring palliative care and identify EoL patients | Needs to be a consistent approach to developing and upskilling nurses across the region | Whole IT system is a real problem. We need an integrated system such a system one for all service to access in real time | One of the main obstacles to achieving transformation is that we work in different ways across the region | Broader, earlier community based preventative support and a focus on population outcome elements of palliative care is needed |

# 8. Appendix 3: Draft WWCP Dementia strategy, vision and service model pathway

# West Wales Care Partnership (WWCP)draft dementia strategy and service model pathway

Whilst developing the HDuHB PEOLC strategy, Attain were also commissioned by the WWCP to develop a dementia strategy, vision and service model pathway for West Wales. The following pages contain the draft dementia service vision and service model pathway which builds on the Attain dementia best practice research report circulated to WWCP Dementia Steering Group 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, people living with dementia (PLWD) and their carers we would expect this model pathway to be further developed. Given that a dementia diagnosis is a palliative diagnosis, this service model pathway converges with the PEOLC service model pathway. Both pathways have similarities e.g. the need for a case manager co-ordinator type role, a centralised care plan, MDT way of working with the patient at the centre.

# 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.
- 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 COVID-19 upon those with dementia is not available at this stage
- Stakeholders have identified that COVID-19 has impacted timely diagnosis due to late presentations

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-19 upon those with dementia and their carers
- The waiting time for diagnosis should be reviewed and monitored; solutions should be found to address long waiting times

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

# DRAFT - West Wales vision for dementia services

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

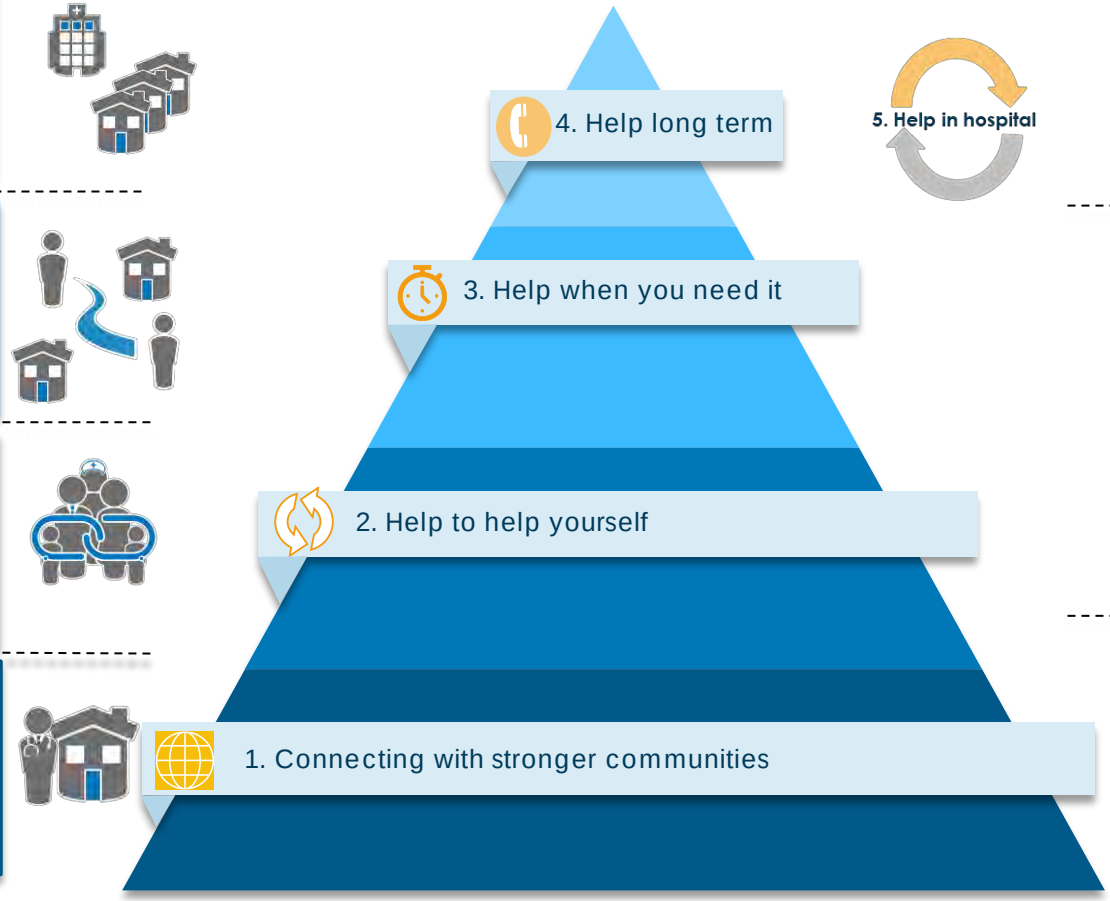
Specialist dementia care support – in the community and in hospital

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

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- 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

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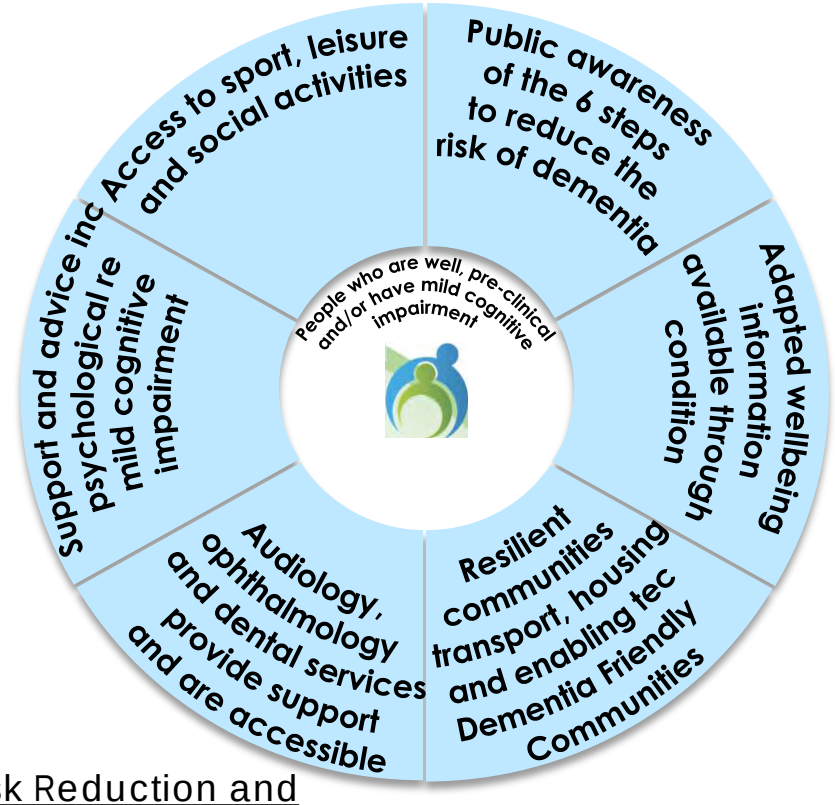
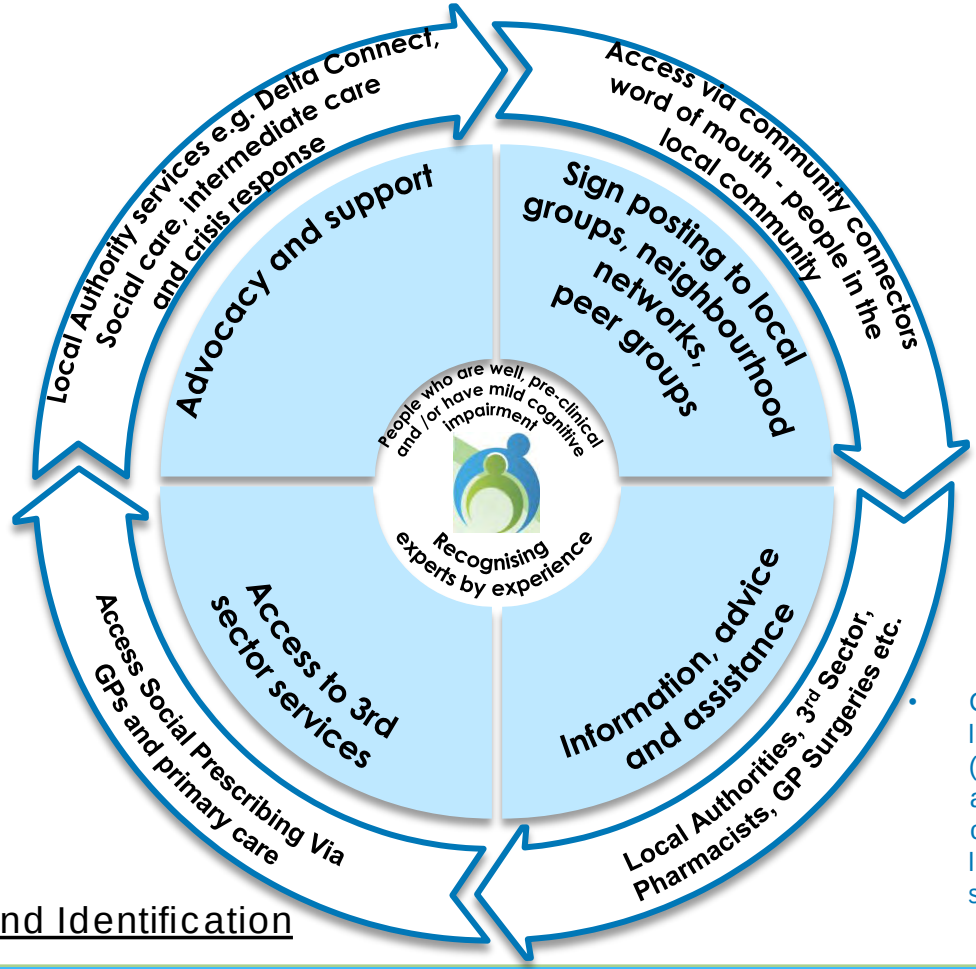
- New ways of working expanding the capacity of the Good Work training framework and new workforce roles e.g. Dementia care co-ordinators/case managers
- Using technology to empower PLWD and their carers and our staff.
- Commissioning and provision of primary care services at scale
- Interpret population 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

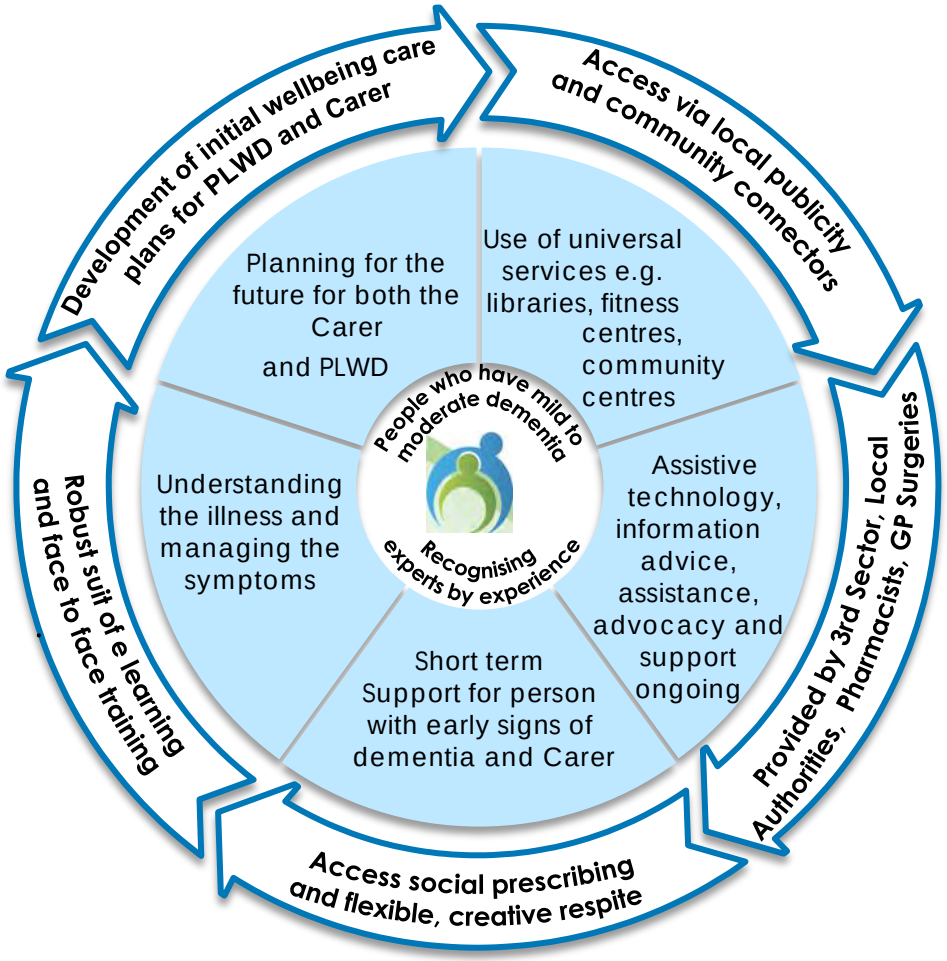
Recognition and Identification

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

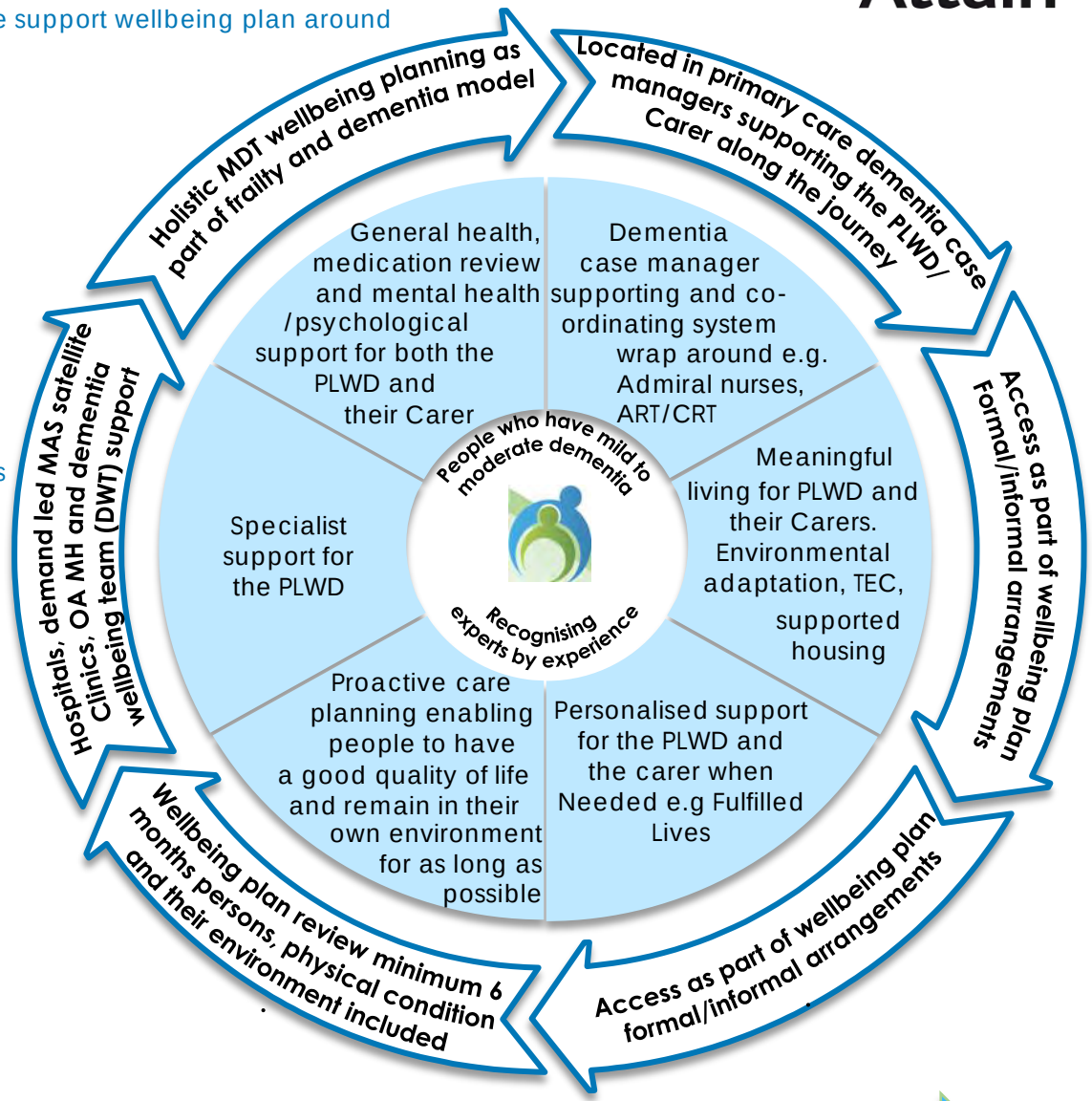
- Enabling generic services (e.g. social work, domiciliary care, care homes, district nursing, OT, physio etc.) to support people with dementia - education - what signs to look for and what to expect
- Widening those who can diagnose – training and advice from the Dementia Wellbeing Team (DWT)




## 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

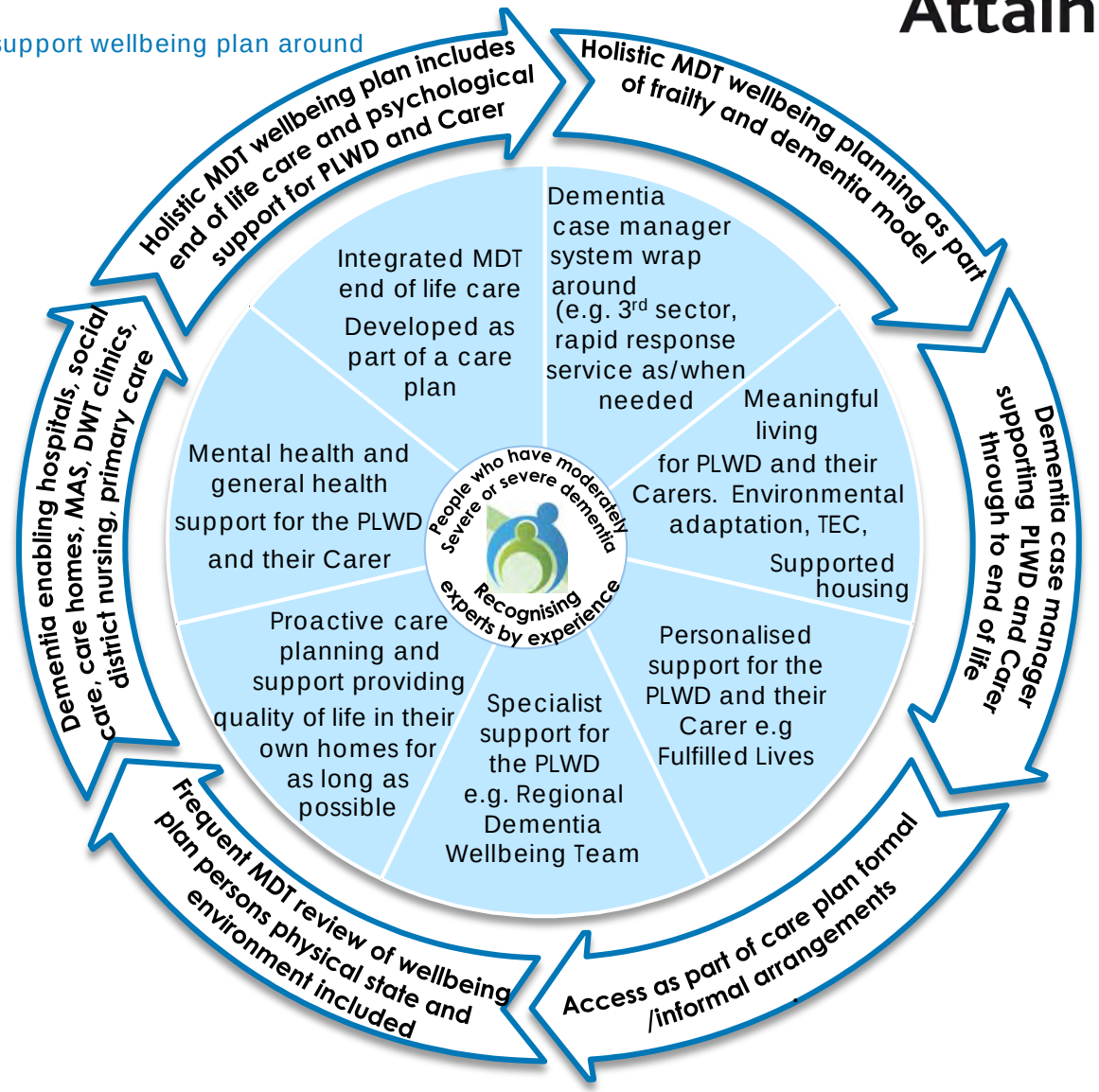
# What good looks like for West Wales – The draft dementia wellbeing pathway

Attain

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

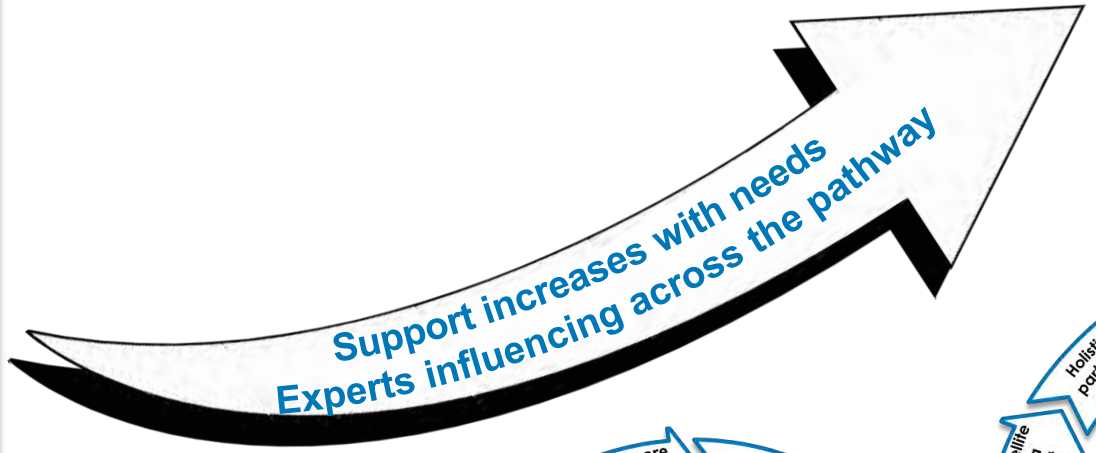


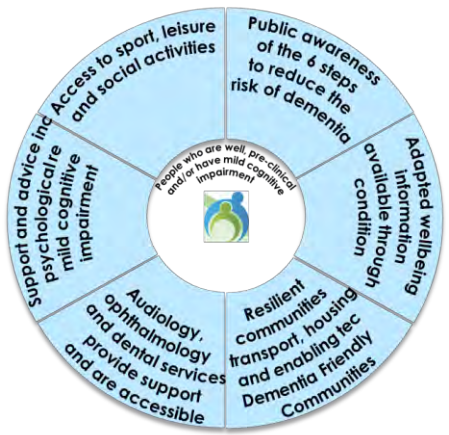

- Implementation of the Good Work Framework - we need to consider the learning and development needs of everyone who is affected in some way by dementia. This includes people living with dementia, carers, frontline staff, managers, commissioners, regulators, researchers, shopkeepers, next door neighbours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

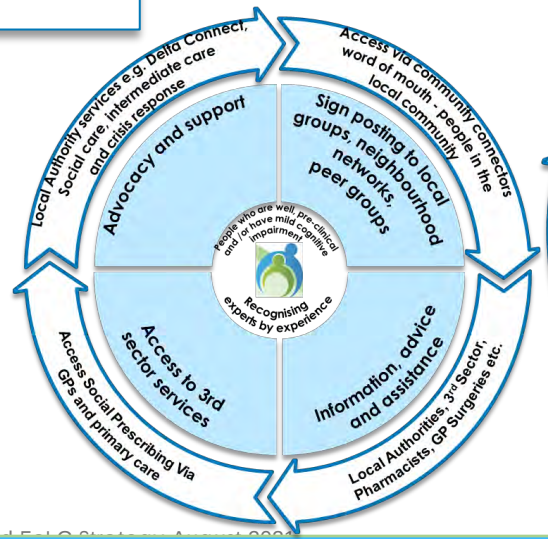
Under pinned by access to assistive technology, training - Implementation of the Recognition and Good Work Frameworks

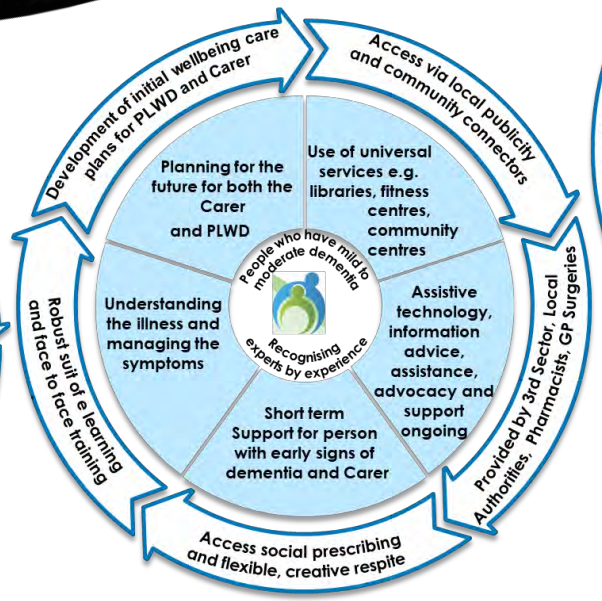
# What good looks like for West Wales – The draft dementia wellbeing pathway

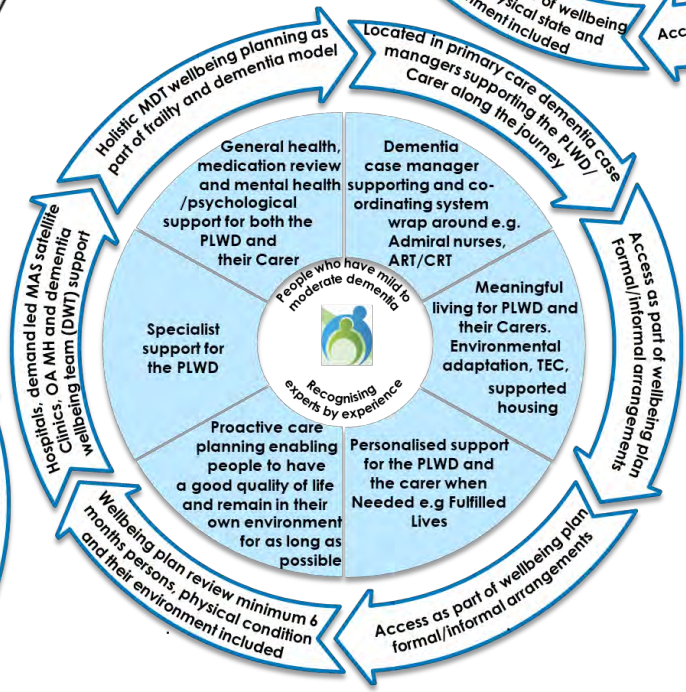
- This draft model, illustrates a new more joined up way of providing services. It is based on best practice and existing services within West Wales. The model requires further co-design with frontline staff, PLWD and their carers
- The service model should be underpinned with an agreed set of service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

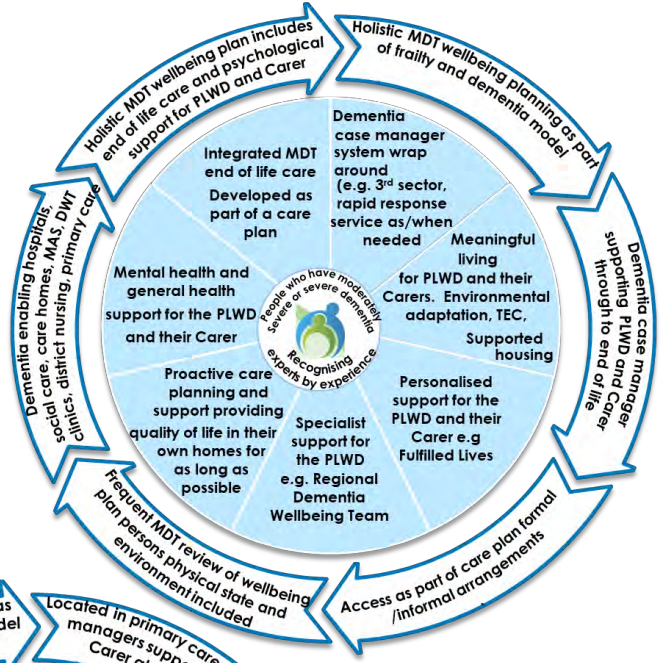
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# 9. Appendix 4: Best practice model – SWAN and Cygnet EoLC

**Our Hospitals**

- Salford Royal
- The Royal Oldham Hospital
- North Manchester General Hospital
- Fairfield General Hospital
- Rochdale Infirmary
- Floyd Unit
- Community Services

# SWAN and Cygnet Model for End of Life and Bereavement Care

The Swan model of End of Life and Bereavement Care was first implemented at Salford Royal Foundation Trust in 2012 and has since been rolled out across nearly 50 Care Organisations throughout the UK. Under the initiative, a swan sign is used to make staff aware that a patient is nearing death and that extra attention should be paid to the patient's needs and the needs of their loved ones.

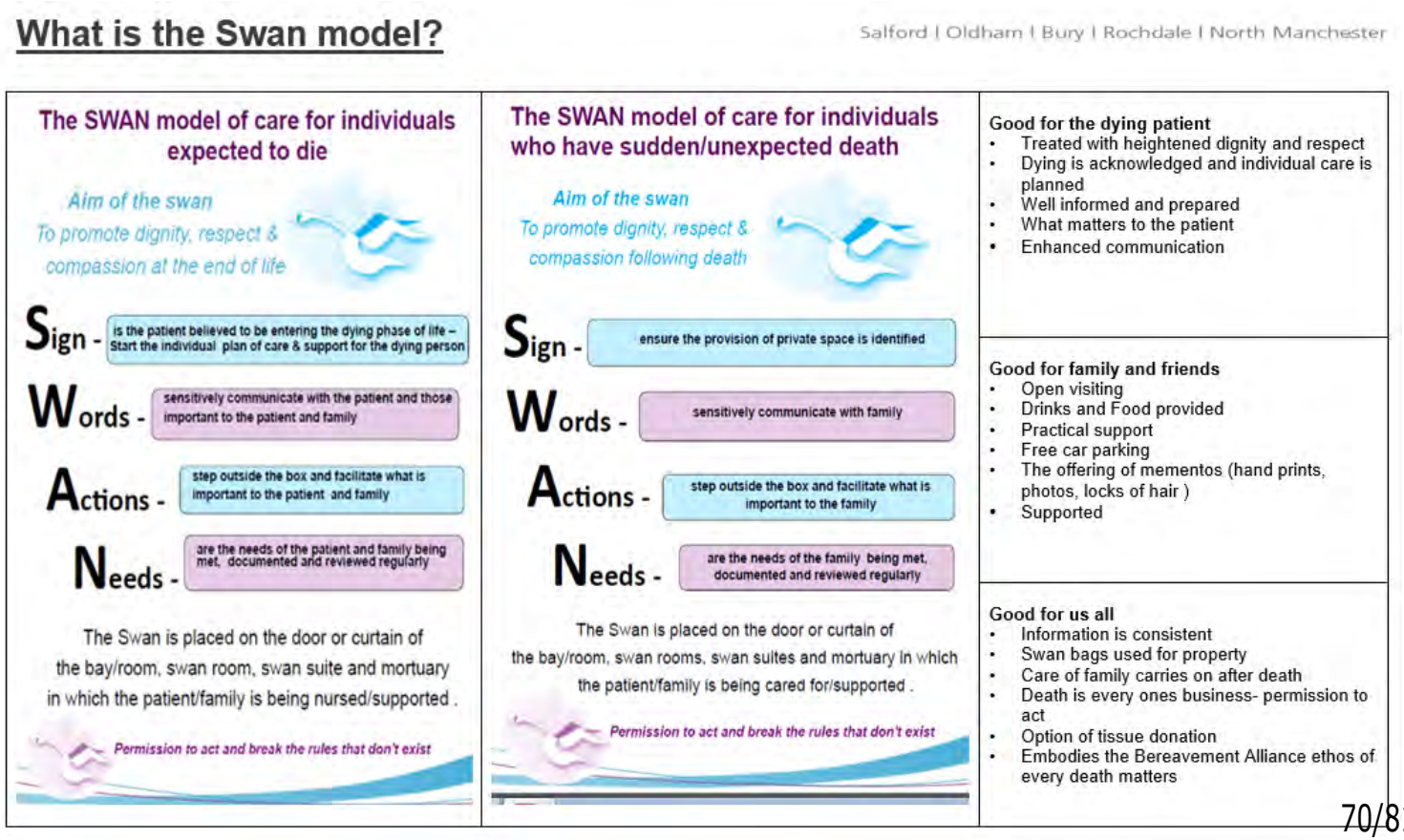
The Swan model of care is about providing excellent, individualised end of life and bereavement care for every patient and every family, every time. It is patient and family focused and centres on meeting the unique needs of each individual and their loved ones.

The Swan model is instigated at the point of recognition of dying and is used to support care throughout end of life, into bereavement and beyond. Staff inform the family wherever possible of what the Swan model means and a Swan sign is placed on the door or curtain of the area in which the dying person is being cared for. It acts as a visual reminder for all staff to employ the principles of the Swan model in their care for that person and their loved ones, and reminds everyone, including other visitors, to be mindful of maintaining as peaceful an environment as possible.

The Swan is an enabling model which supports generalists to be specialists in end of life and bereavement care. It's ethos is about empowering staff and giving them permission to care and to break the rules that don't exist.

In response to COVID-19, Northern Care Alliance introduced "Cygnets" to help deliver aspects of the SWAN model in care settings and ensure people were not dying alone.
The Cygnets were a non-specialist team of redeployed and temporary staff who were named as such to let people know that it was not their usual area of expertise.

A new study carried out by London South Bank University will evaluate the effectiveness of both the SWAN and Cygnet models and the potential transferability to other settings.



# 10. Appendix 5: The ReSPCT Form

# The ReSPECT form

The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices.

These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.

Patient preferences and clinical recommendations are recorded on a non-legally binding form which can be reviewed and adapted if circumstances change.

The ReSPECT process can be for anyone but has increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest. Some people will want to record their care and treatment preferences for other reasons.

The ReSPECT process is increasingly being adopted within health and care communities around the UK.

# 11. Appendix 6: Best practice model – Midhurst Macmillan Service

# The Midhurst Macmillan community MDT palliative care service

## Summary of Model

A community-based, consultant led, specialist palliative care service in a rural community in the south of England.

The service seeks to provide direct care and support to patients in the last 12 months of life to prevent unnecessary hospital admissions and enable them to live at home and die in the place of their choice
The service is provided by a multidisciplinary team consisting of palliative care consultants, specialist nurses, health care support workers, allied health professionals and volunteers. Patients are allocated to one of six clinical nurse specialists (CNSs) ensuring continuity of care. A seventh CNS covers for others on leave or sick leave. Volunteers provide additional support through activities such as shopping or gardening. Information about patients is shared at multidisciplinary meetings held daily and weekly and logged on the internal IT system. Team members also use telephone and face-to-face communication to update each other about a patient's status, and to liaise with GPs and community health teams.
The Midhurst Macmillan Service has access to palliative care consultants based in the community who are able to provide specialist interventions that are normally delivered in hospital at the patient's home.

https://www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16353

https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/midhurstsummary(2).pdf

https://onlinelibrary.wiley.com/doi/full/10.1111/ecc.12195

https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/midhurst-macmillan-coordinated-care-case-study-kings-fund-aug13.pdf

## Lessons learned

- Awareness raising and relationship-building from GPs, community staff, hospital consultants, volunteers and local people
- Holistic care assessment and personalized care plan – a single assessment process of both health and social care needs of patient and family now and future
- Multiple referrals to a single entry point. All referrals come into the service and are assigned a clinical nurse specialist
- Dedicated care co-ordination – principle point of contact for patient, family and care providers
- Rapid access to care from an MDT. The service operates 12 hrs a day with access to an on-call clinician out of hours

## Impact

185 of the 348 patients treated in one year died at home, and for 183 (99 per cent), this was the place of their choice

Feedback from impact review

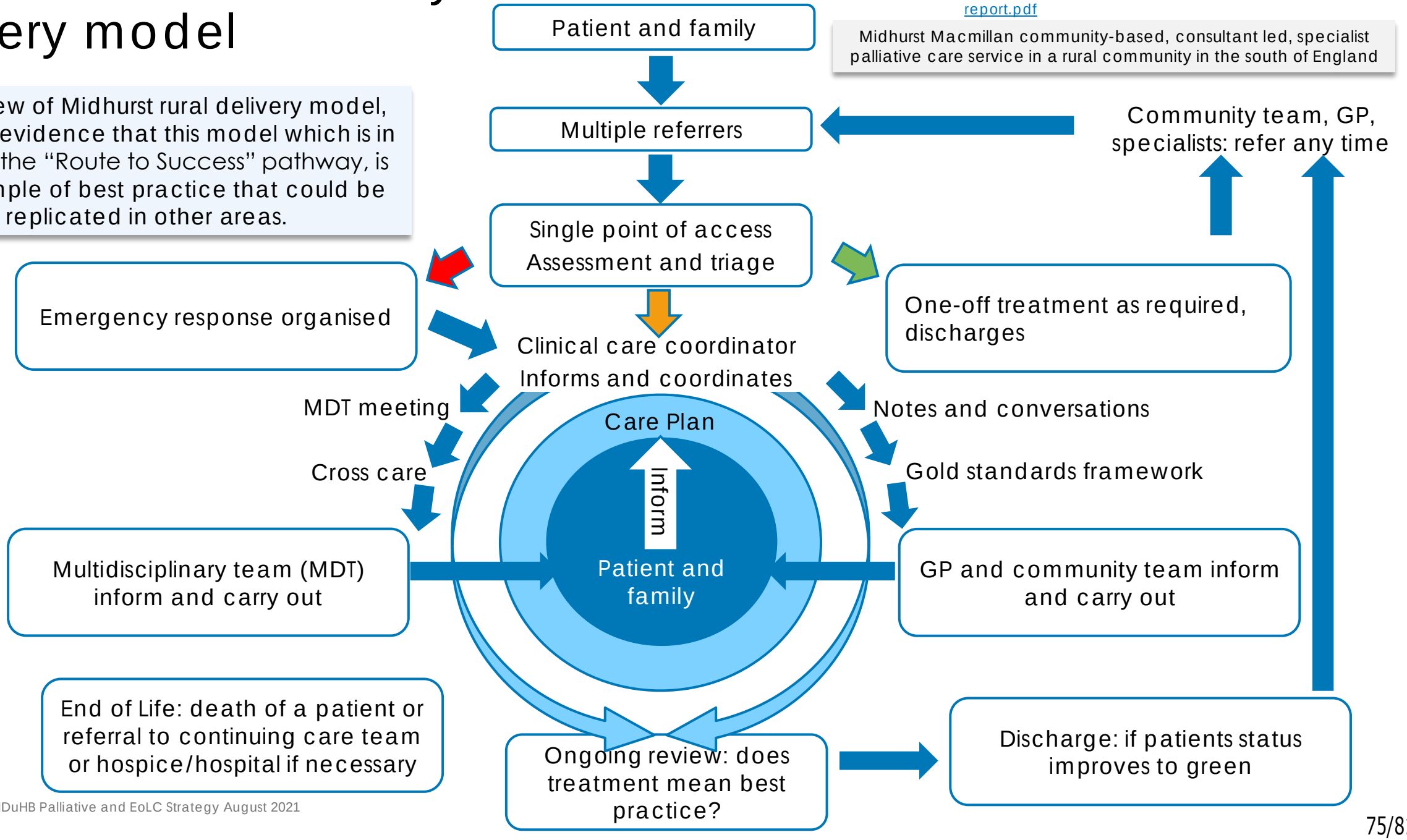
- "[We've] worked on having a much more flexible approach so that one person can go in and do tasks that perhaps they might be a little bit overqualified to do but it's much better; they're qualified to do those tasks and they're there in the patient's house"
- [A key benefit is] access to immediate medication
- Providing care in the home and remove the stress, exhaustion and recovery required from hospital trips
- Estimated reduction in NHS costs of 20% when patients referred early
- The Midhurst model can work effectively alongside high-quality hospice and hospital palliative care services
- Encourages early assessment of palliative care need at the point of inpatient admission
- Expands specialist capacity without incurring significant capital costs

# Midhurst is a community based delivery model

https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/midhurst-final-overall-report.pdf

Midhurst Macmillan community-based, consultant led, specialist palliative care service in a rural community in the south of England

The review of Midhurst rural delivery model, provides evidence that this model which is in line with the "Route to Success" pathway, is an example of best practice that could be replicated in other areas.



# Changes to the Midhurst Service since 2013

| Improvements Made to the Midhurst Service | Benefits | Challenges |
|---|---|---|
| IT interoperability – GP practices in 2 out of 3 of the commissioning CCGs now have SystmOne, which the Macmillan service now uses. | Having one IT system across the area greatly improves communication and reduces time. | 1 CCG's GPs use Emis, so there continue to be communication challenges updating GPs in this CCG area. |
| IT access – all staff now have access to laptops and ipads when out and about. | Staff can type up notes in real time. | Using technology when having difficult conversations interrupts the flow. Staff prefer not to type up notes in patient's homes and do it later. |
| Training - Sage and Time Communication training | This has been a hugely beneficial training programme supporting all the workforce involved in palliative and EoLC to have difficult conversations with patients, including volunteers and porters through to consultants.<br>• Level 1 covers supporting a patient in distress.<br>• Level 2 covers an introduction to drawing up Advanced Care Plans | GPs accessing the training is a challenge, although with MS teams this is made easier. Training is now more inhouse rather than outward facing as it once was. Sage and Time is less helpful for those presenting with late-stage dementia, but elements of it are still used. |
| The patient group | The cancer /non-cancer split is now 70:30, | There has been an increase in those with dementia and other comorbidities, and frailty accessing the service. |
| Support to Care Homes | Additional funding was secured for 1 consultant and 1 CNS to undertake one off reviews and to develop a care plan for residents. | Continuation of funding subject to success of the pilot. |

# 13. Appendix 7: Approach to managing the programme of work

# What does good programme management look like?

# The components of a good programme (1)

| | Vision, Leadership and Culture | Programme Governance | Stakeholder Management and Communication | Planning and resourcing |
|---|---|---|---|---|
| What good looks like | • Clear shared vision owned by all partners<br>• Joined up leadership fully engaged<br>• 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<br>• Clear process in place for escalating risks, issues and opportunities<br>• Lean structure; time is used effectively, with a balance between discussion and action<br>• Programme team have a clear understanding of roles and responsibilities<br>• Patient / public engagement embedded in programme governance<br>• Clinical leadership embedded in programme governance | • Stakeholder mapping and communications plans in place<br>• Key stakeholder relationships are managed proactively<br>• External communications are targeted at relevant audiences and accessible language / communication formats are used<br>• Internal communications to keep programme team informed, support team dynamics<br>• 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<br>• Each workstream has a clear plan, setting out what will be delivered, how and when<br>• Interdependencies have been mapped<br>• Resources required to deliver the programme have been mapped and investment agreed<br>• OD requirements mapped and strategy in place for coordinated delivery |
| Tools and products | • Vision / mission / values statement<br>• Memorandum of Understanding / partnership agreement<br>• Outline Business Case | • Programme Governance Structure Chart(s)<br>• Terms of Reference<br>• Meetings forward plan<br>• Programme team organisation chart<br>• Roles / responsibilities matrix<br>• Reporting and risk/issue escalation processes<br>• Templates for meeting agendas, notes and actions, highlight reports | • Programme Communications and Engagement Strategy / Action Plan<br>• Stakeholder mapping tool<br>• Internal communications process<br>• Equality Impact Assessment process and documentation<br>• Core set of programme documentation / presentations / branded templates for use with a range of audiences<br>• Engagement tracker | • High level programme plan with milestones and critical dependencies<br>• Detailed programme plan<br>• PMO work plan<br>• Recruitment and resourcing tracker (programme team)<br>• Business case process, template and guidance<br>• 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<br>• Robust methodology in place to track benefits across all work streams<br>• Baseline data captured<br>• Outcome measures are targeted to enable monitoring of specific interventions – to see whether a change is effective<br>• 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<br>• Clear processes are in place for identifying and tracking risks, with levels of escalation<br>• Robust, consistent documentation used across the programme to support proactive risk management and provide an audit trail<br>• 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<br>• Change control in place for core documents/tools<br>• PMO team is able to support operational staff / work streams by reducing the documentation burden<br>• PMO advises and supports programme team / delivery leads; skills development, quality improvement<br>• Quality assurance is in place for key deliverables | • Budget agreed for programme resourcing<br>• Robust mechanisms in place for management of programme budget – budget setting, change control, monitoring, accounts payable, procurement |
| Tools and products | • Business Case/ Investment Appraisal<br>• Benefits/outcomes framework, capturing key performance indicators, outcome measures, metrics etc)<br>• Benefits realisation plan and tracking tool | • Programme risk and issue register<br>• Risk management process and guidance | • Programme contact list<br>• Information Management protocols and filing structure<br>• Shared programme calendar / inbox | • Programme Financial management process / control<br>• Programme budget |

# Contacts

| | | |
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