

# Bite Size Dementia Diagnosis Rates Communication Resources

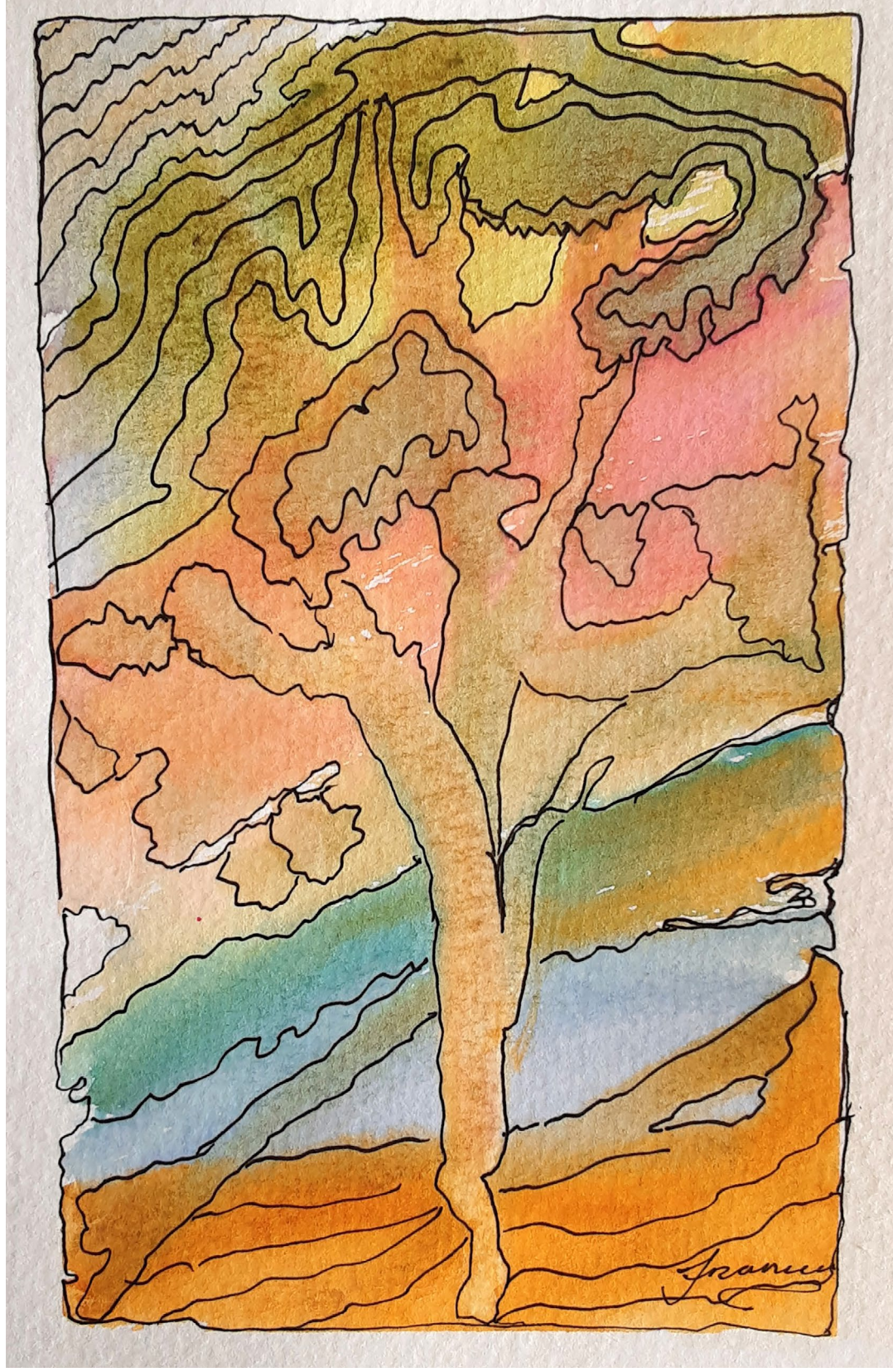
Improvement activities and resources to  
increase dementia awareness and recording  
of the dementia diagnostic rates

Caring

Understanding

Important Possibility

Resourceful



# Memory Assessment Services

Empowering Hope

Rewarding

Communication

Supportive

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# Introduction

## 1.1 Engagement and Communication Activity

# "What is this... and **Who** is it for?"

Improvement Cymru has worked with memory assessment services (MAS), partner organisations and people living with dementia<sup>1</sup> to create communication improvement activities and resources to improve dementia diagnosis rates in Wales. The 'foundation' resource is the 'READ Code Reminders, Checklist and Guidance'

## 1.2 The Context and Aims

# "Why Implement... this **Activity**?"

The Dementia Action Plan (2018) states Wales needs to increase its dementia diagnostic rates by 3% annually from the recorded low rate of 53% in 2017/18. In comparison to the other three nations, the Wales dementia diagnostic rate was the lowest recorded, significantly, 20% below Northern Ireland's.

In planning to deliver the standards, many regions are reviewing their current services and resources against the recorded population numbers. Knowing who is living with dementia in the region has become increasingly important during the pandemic to ensure there is a coordinated, targeted offer of vaccines and other supporting health and social care interventions delivered.

<sup>1</sup> These resources have been developed with people living with dementia, MAS regional workstream leads, general practice managers, MAS teams, practitioners of all disciplines and grades and a number partners including the Alzheimer's Society Cymru.

Health based information is recorded using the dementia register which provides a count of population based dementia diagnostic rates. Each GP surgery in Wales is commissioned to hold a dementia register which enables Welsh Government to determine the population based dementia diagnostic rates and forms part of the Quality Assurance and Improvement Framework (QAIF) contract for GPs. All general practices in Wales rely on the clarity of diagnostic information from all connecting services to be able to accurately capture information.

The position is shown in analysis on the StatsWales website, [here](#).

## Quality Assurance and Improvement Framework (QAIF) 2019-20

Estimated number of undiagnosed people aged 65 or over with dementia by local health board 2019-20

Local Health Board	Number diagnosed (QAIF)	Males: with dementia (CFAS II)	Female: with dementia (CFAS II)	Persons: with dementia (CFAS II)	Number undiagnosed (CFAS II - QAIF)	% diagnosed (QAIF/CFAS II)
<b>Wales</b>	<b>22,005</b>	<b>15,360</b>	<b>26,097</b>	<b>41,457</b>	<b>19,451</b>	<b>53.1%</b>
Swansea Bay University Health Board	2,798	1,773	3,201	4,974	2,175	56.3%
Powys Teaching Health Board	981	875	1,439	2,314	1,333	42.4%
Hywel Dda University Health Board	2,859	2,309	3,733	6,043	3,184	47.3%
Cwm Taf Morgannwg University Health Board	2,733	1,979	3,284	5,263	2,530	51.9%
Cardiff and Vale University Health Board	3,269	1,787	3,409	5,195	1,927	62.9%
Betsi Cadwaladr University Health Board	5,268	3,883	6,429	10,312	5,044	51.1%
Aneurin Bevan University Health Board	4,097	2,754	4,602	7,356	3,259	55.7%

Source: Quality Assurance and Improvement Framework (QAIF), CFAS II study preferences, 2019 ONS mid-year population estimates

The All Wales Dementia Pathway of Standards (2021) aims to ensure when a person is diagnosed with dementia, wherever they live in Wales, they receive a range of interventions, care and support which will enable them to maximise their skills, abilities and quality of life. This communication focuses on **Standard 3** but also connects and aligns with all 20 standards.

Assurance...  
and **Improvement**"

## Standard 3

### Standard 3 states:

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

### READ Codes are used in Wales to capture the rates of dementia diagnosis. READ Codes include the following:

#### List of READ Codes

**Eu00. Alzheimer's dementia \***

**Eu01. Vascular dementia \***

**Eu025 Dementia with Lewy Bodies**

**Eu002 Mixed dementia**

**Eu057 Mild cognitive impairment (MCI)**

**Eu02z Other dementia** (i.e. Frontotemporal dementia, Parkinson's disease dementia, alcohol related dementia etc.)

**\*Please be aware all READ Codes have 5 digits, so in 2 codes (see \*) a full stop must be included**

All correspondence to and within statutory services are expected to record the dementia diagnosis and the READ Code (READ Code Health Circular WG February 2022).

### READ Codes will be clearly displayed on correspondence for example:

**DIAGNOSIS: Lewy Body**

**Dementia READ CODE: Eu025**

## The READ Codes are recorded by the following services:

- Memory assessment services (MAS), including learning disability (LD) services
- GP surgeries and primary care services
- Secondary care services e.g. neurology, psychiatric liaison services
- Wherever dementia is diagnosed and where dementia care is delivered.

The READ Code is recorded on all information and communications are shared between services to ensure an accurate diagnosis. Once the READ Code is recorded it is entered onto the dementia register and shared with the person living with dementia and their carer (if they wish to receive this information).

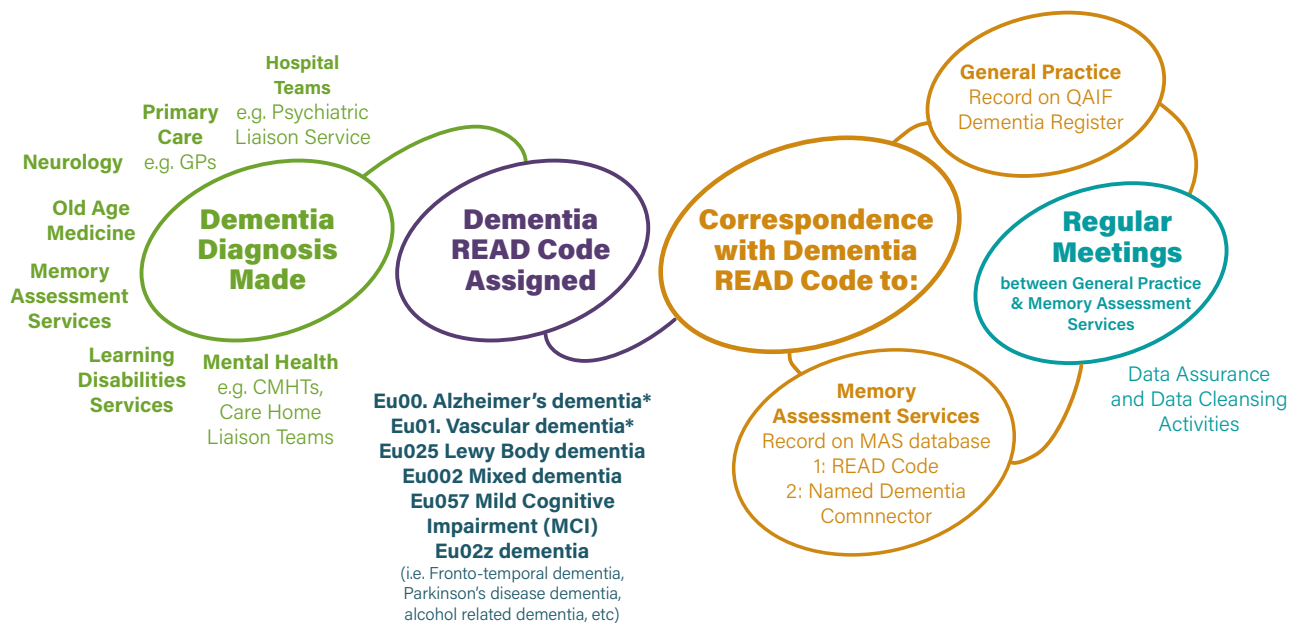
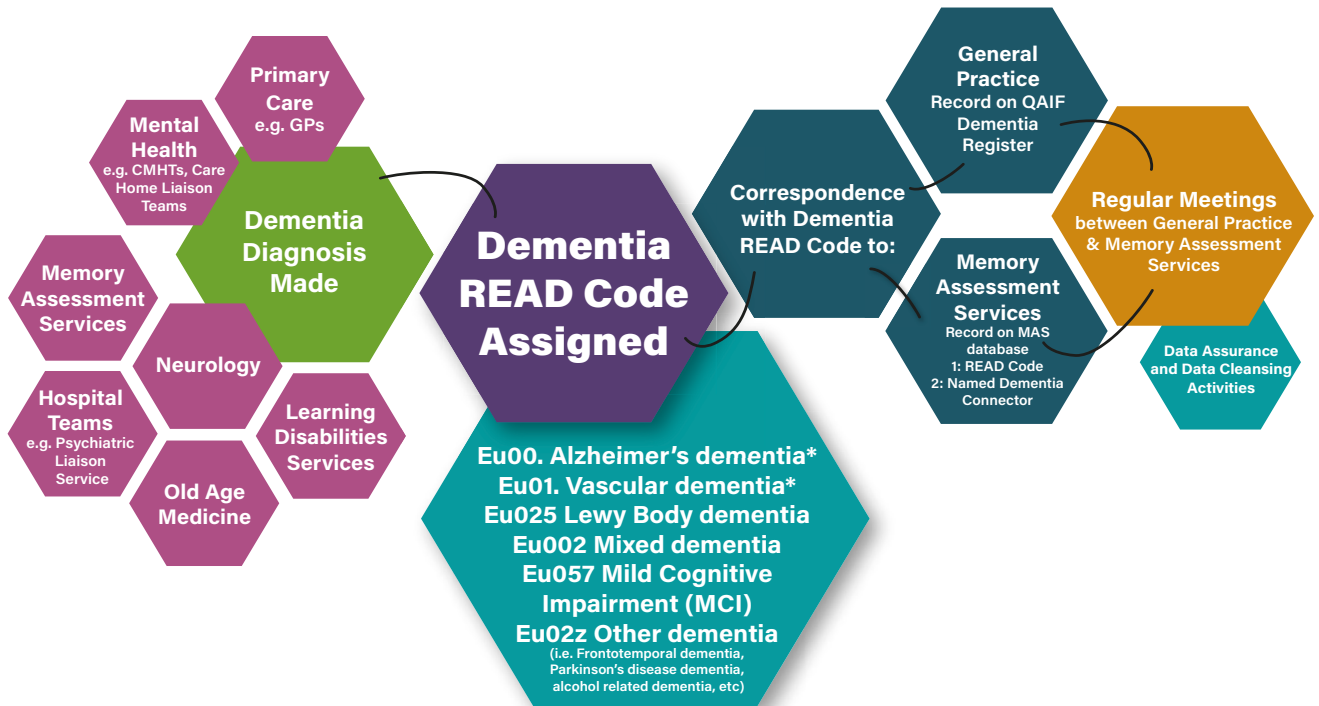
All health services and primary care databases will use the READ Codes. This will ensure the identified READ Code can be added to the register that collates dementia diagnosis rates and is maintained by the GP.

**MAS will also maintain a database with diagnosis information as it is important all people diagnosed with dementia in the locality are captured. This will require MAS to work in partnership with GPs and may require regular meetings between both partners to review data and data cleanse. The person's named dementia connector will also be recorded within the database.**

## Using the resources in this pack will achieve the following aims:

- Support conversations between MAS and general practice managers to assist relationships and partnership working
- Assist the READ Code information to be accurately reported and uploaded onto the primary care general practice register
- Support improving dementia awareness and understanding across the workforce and public
- Enable regions to identify the dementia population group and thus support better health and care outcomes for people living with dementia and their supporters
- Aid better identification of people who maybe struggling with a cognitive impairment to enable them to take the steps to access care and support.

## The flow of information and data capture of dementia diagnostic READ Codes



# "Why Implement... this Activity?"

Using the bite size resources will enable regions to focus on targeted improvement work so they can support effective implementation, spread and scale whilst measuring the impact.

Regions should currently be implementing the Dementia READ Code practice as outlined by Welsh Health Circular 'Recording of Dementia READ Codes' (Welsh Government, February 2022).

Additional bite size activities will be added to this resource as the need is identified by the MAS steering group.

Resources and activities are complementary to pre-existing initiatives, for example, Alzheimer's Society Cymru Dementia Friends and Dementia Friendly Communities.

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## 1.4 Other Resources from External Bodies

Regions may also want to consider using other types of posters and resources to advertise any local support other organisations provide e.g. Alzheimer's Society, Dementia Powys Matters and National Dementia Helpline.

### Improvement Cymru Padlet and Website

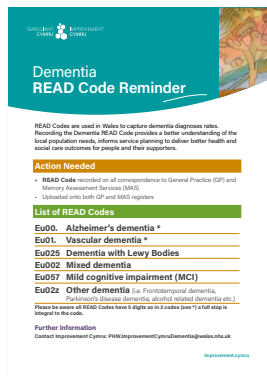
All of the resources listed below can be found on the Improvement Cymru website's dementia pages.

If you have additional resources to share with others please email them to [PHW.ImprovementCymruDementia@wales.nhs.uk](mailto:PHW.ImprovementCymruDementia@wales.nhs.uk).

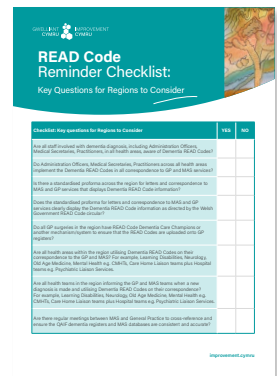
# Bite Size Communication Resources: READ Code Reminders, Checklist and Guidance

## What is contained in this communication

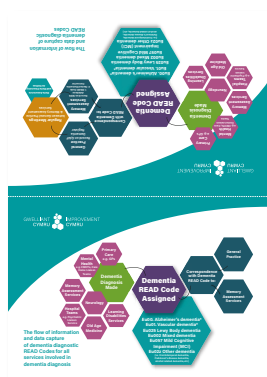
**Poster** to be displayed in areas to support communication of the READ Codes and their purpose. See Appendix 1 for poster which can, for example, be printed out or used on electronic notice boards.



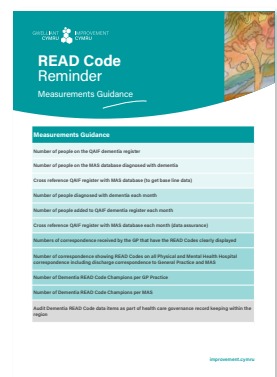
**Checklist** – key questions for regions to consider to ensure READ Codes are being assigned and mechanisms and systems for recording are in place. See Appendix 3 for checklist – a separate document will be available for relevant staff to save and action.



**Infographic / Deskcard** showing the flow of information and data capture of dementia diagnostic READ Codes across services. See Appendix 2 for Infographic / Deskcard.



**Measurements Guidance** – key measurements for regions to consider to ensure READ Codes are being assigned and mechanisms and systems for recording are in place. See Appendix 4 for guidance – a separate document will be available for relevant staff to save and action.



## Who should be using these resources?

### Poster and Infographic / Deskcard

All services involved with diagnosing dementia from MAS, neurology, old age medicine, mental health, learning disabilities, hospital teams i.e. psychiatric liaison services, primary care, general practice services. This will include administration officers, medical secretaries, managers and practitioners.

### Checklist and Measurement Guidance

Key persons responsible for managing and driving change in areas where dementia diagnosis takes place e.g. team leads and managers.

## Why should you be using these resources?

- To support conversations and building relationships between general practices and MAS managers and team leads
- To help all staff and services understand the READ Codes' importance and purpose
- Practice based evidence suggests individuals involved in communicating READ Code information, e.g. administration officers, medical secretaries and practitioners, are key to ensuring that READ Code information is communicated and recorded onto the dementia registers
- Having a general practice "READ Code Dementia Care Champion" responsible for ensuring the codes are entered onto the GP registers has been identified as vital to support accurate recording
- "READ Code MAS Champions" to connect with GPs are identified as beneficial to ensure that READ Code data reliably reaches and accurately correlates with the GP dementia diagnostic register. (If you don't have a Dementia Champion in MAS or a GP Champion consider creating one)
- The Welsh Health Circular Recording of Dementia READ Codes (Welsh Government February 2022) identifies that all health services and primary care databases will use the dementia READ Codes

# Appendix 1

## READ Code Reminder Poster



# Dementia READ Code Reminder

READ Codes are used in Wales to capture dementia diagnoses rates. Recording the Dementia READ Code provides a better understanding of the local population needs, informs service planning to deliver better health and social care outcomes for people and their supporters.

## Action Needed

- **READ Code** recorded on all correspondence to General Practice (GP) and Memory Assessment Services (MAS)
- Uploaded onto both GP and MAS registers

## List of READ Codes

**Eu00. Alzheimer's dementia \***

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**Eu01. Vascular dementia \***

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**Eu025 Dementia with Lewy Bodies**

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**Eu002 Mixed dementia**

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**Eu057 Mild cognitive impairment (MCI)**

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**Eu02z Other dementia** (i.e. Frontotemporal dementia, Parkinson's disease dementia, alcohol related dementia etc.)

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Please be aware all READ Codes have 5 digits so in 2 codes (see \*) a full stop is integral to the code.

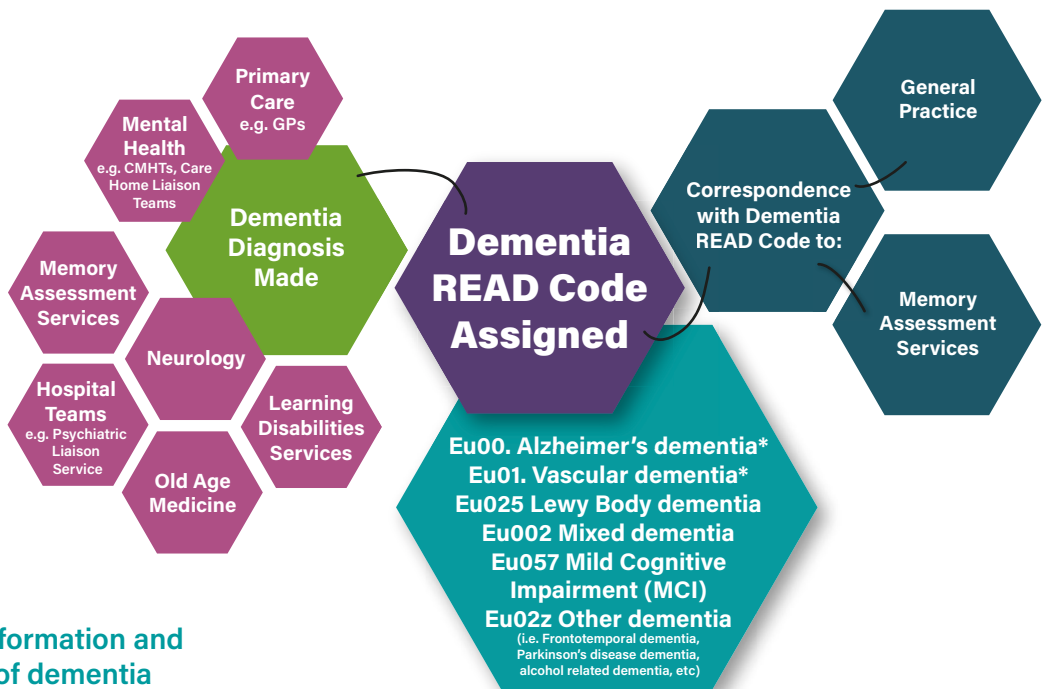
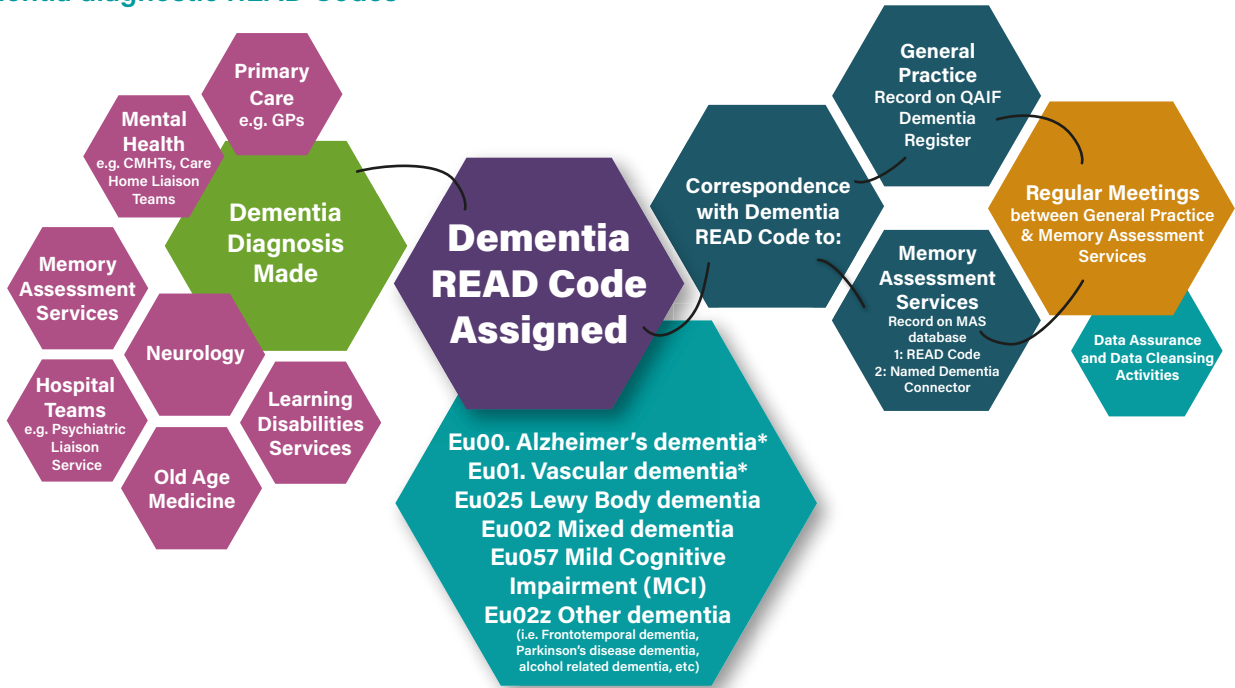
## Further Information

Contact Improvement Cymru: [PHW.ImprovementCymruDementia@wales.nhs.uk](mailto:PHW.ImprovementCymruDementia@wales.nhs.uk)

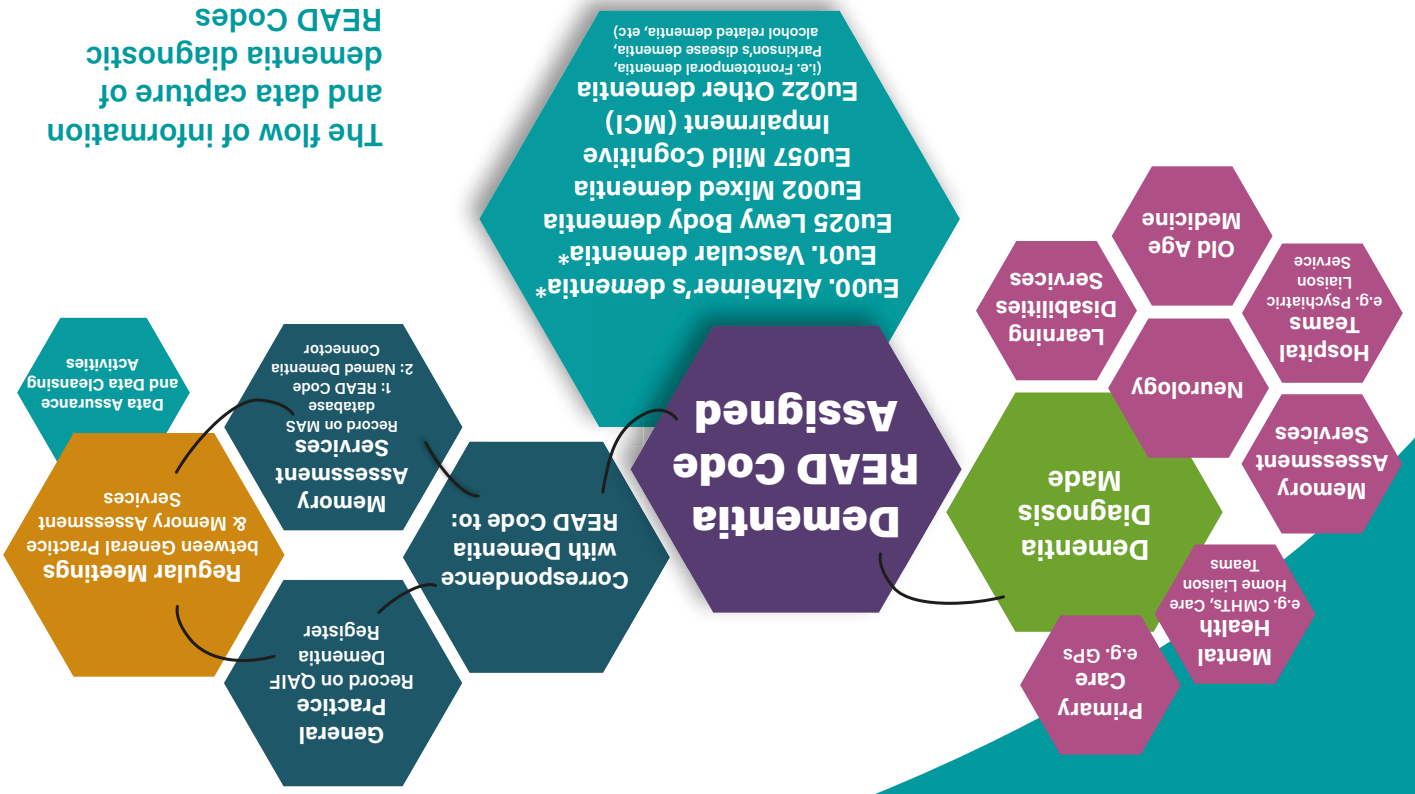
# Appendix 2

READ Code Reminder: Infographic / Deskcard

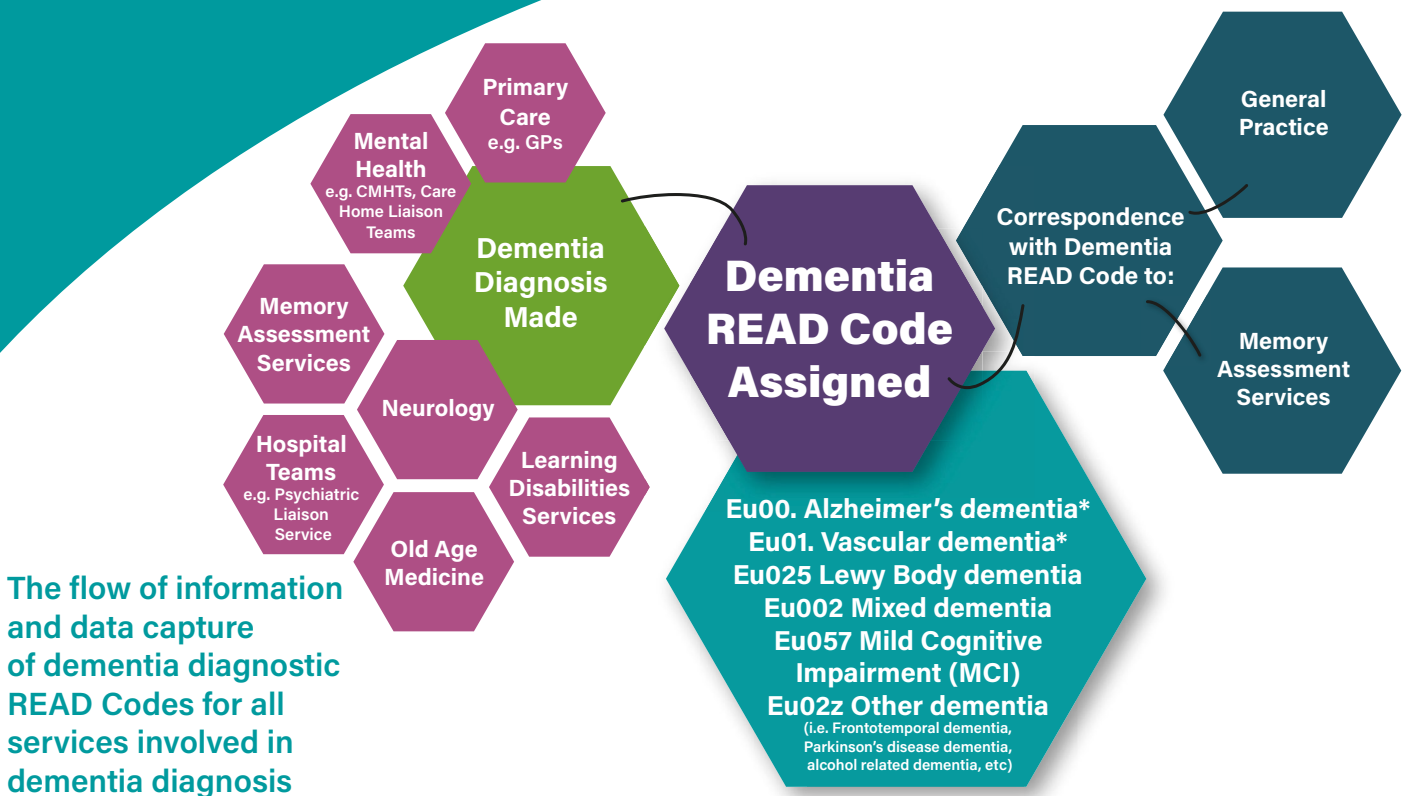
The flow of information and data capture of dementia diagnostic READ Codes



The flow of information and data capture of dementia diagnostic READ Codes for all services involved in dementia diagnosis

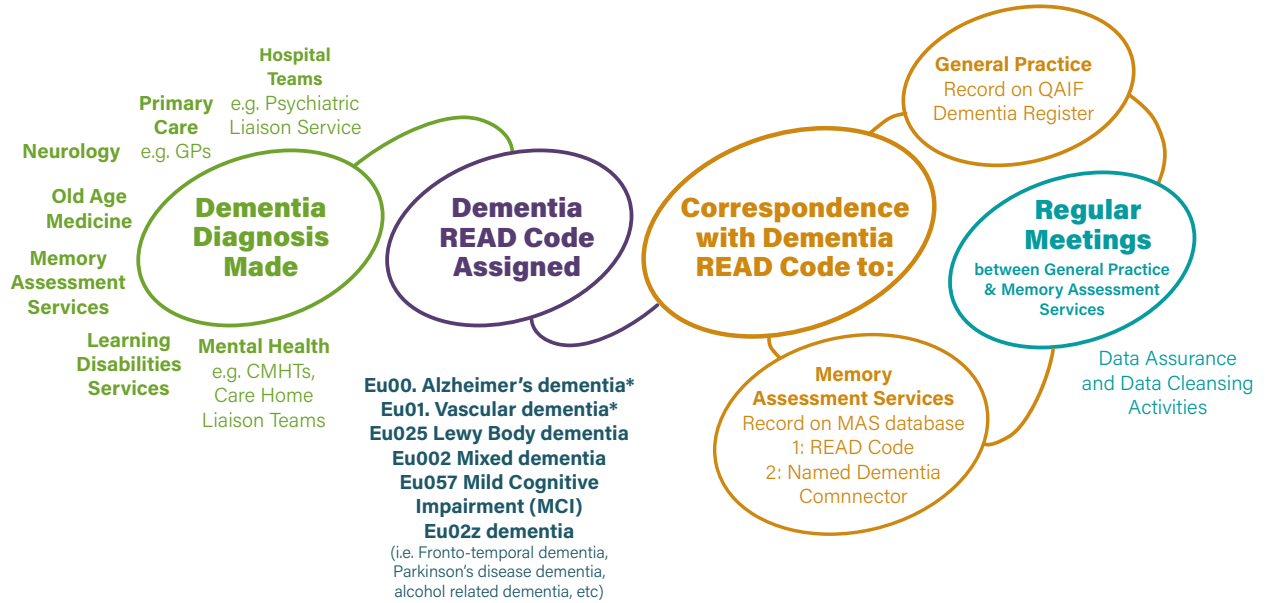


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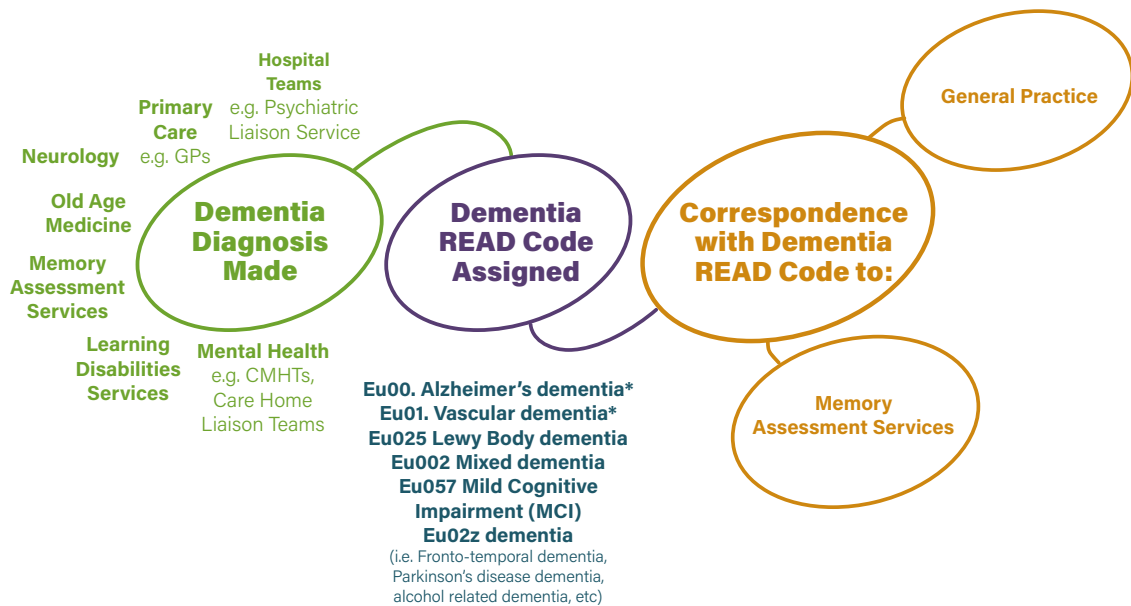


The flow of information and data capture of dementia diagnostic READ Codes for all services involved in dementia diagnosis

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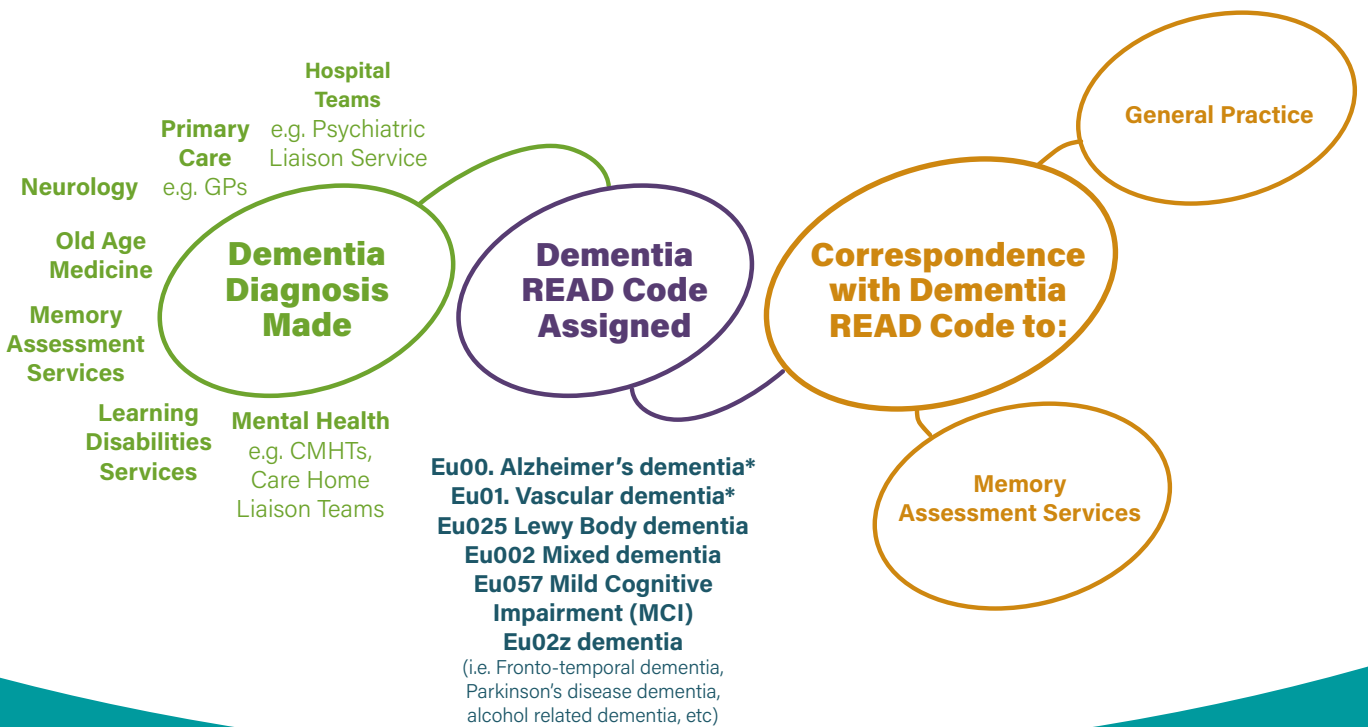




The flow of information and data capture of dementia diagnostic READ Codes



The flow of information and data capture of dementia diagnostic READ Codes for all services involved in dementia diagnostic



# Appendix 3

## READ Code Reminder Checklist

### **Key Questions for Regions to Consider**



# READ Code Reminder Checklist:

## Key Questions for Regions to Consider

Checklist: Key questions for Regions to Consider	YES	NO
Are all staff involved with dementia diagnosis, including Administration Officers, Medical Secretaries, Practitioners, in all health areas, aware of Dementia READ Codes?		
Do Administration Officers, Medical Secretaries, Practitioners across all health areas implement the Dementia READ Codes in all correspondence to GP and MAS services?		
Is there a standardised proforma across the region for letters and correspondence to MAS and GP services that displays Dementia READ Code information?		
Does the standardised proforma for letters and correspondence to MAS and GP services clearly display the Dementia READ Code information as directed by the Welsh Government READ Code circular?		
Do all GP surgeries in the region have READ Code Dementia Care Champions or another mechanism/system to ensure that the READ Codes are uploaded onto GP registers?		
Are all health areas within the region utilising Dementia READ Codes on their correspondence to the GP and MAS? For example, Learning Disabilities, Neurology, Old Age Medicine, Mental Health e.g. CMHTs, Care Home Liaison teams plus Hospital teams e.g. Psychiatric Liaison Services.		
Are all health teams in the region informing the GP and MAS teams when a new diagnosis is made and utilising Dementia READ Codes on their correspondence? For example, Learning Disabilities, Neurology, Old Age Medicine, Mental Health e.g. CMHTs, Care Home Liaison teams plus Hospital teams e.g. Psychiatric Liaison Services.		
Are there regular meetings between MAS and General Practice to cross-reference and ensure the QAIF dementia registers and MAS databases are consistent and accurate?		

# Appendix 4

## READ Code Reminder: Measurements Guidance

# READ Code Reminder

## Measurements Guidance



### Measurements Guidance

Number of people on the QAIF dementia register

Number of people on the MAS database diagnosed with dementia

Cross reference QAIF register with MAS database (to get base line data)

Number of people diagnosed with dementia each month

Number of people added to QAIF dementia register each month

Cross reference QAIF register with MAS database each month (data assurance)

Numbers of correspondence received by the GP that have the READ Codes clearly displayed

Number of correspondence showing READ Codes on all Physical and Mental Health Hospital correspondence including discharge correspondence to General Practice and MAS

Number of Dementia READ Code Champions per GP Practice

Number of Dementia READ Code Champions per MAS

Audit Dementia READ Code data items as part of health care governance record keeping within the region

