

# A review of diagnostic imaging for dementia in Wessex





Wessex Mental Health and Dementia Clinical Network

Authors Rachel Chappell, Dr Chris Kipps Date January 2020 A review of diagnostic imaging for dementia in Wessex

## Contents

Forward	3
Executive Summary	4
Stakeholders	6
Who should read this report?	7
Introduction	8
Aims	10
Methods	11
Online survey	11
Imaging activity data review and data limitations	11
Review of NICE guidelines	11
Review Findings	12
Scanning activity data as a proxy measure for diagnostic dementia imaging	12
The Wessex population	13
Is imaging useful in the dementia pathway?	14
Who is requesting imaging?	15
What is the level of imaging activity in Wessex?	16
New diagnoses of Dementia	17
Cost of scanning for new diagnoses	17
Multiple imaging?	19
Imaging: what modality types are requested?	20
Rationale for choice of imaging modality?	20
Scan and report waiting times?	23
How useful are brain imaging diagnostic reports?	25
What is the impact of imaging on post diagnostic care?	27
Final thoughts from referrers	28
Discussion	29
Conclusions	31
Considerations for future work	32
Appendices	33
Appendix 1: Imaging types and descriptions	33
Appendix 2: Scanning costs	36
Appendix 3: NICE guidelines for imaging	36
Appendix 4: Glossary of terms and abbreviations	40
Wessex Clinical Network: Dementia publications and products	41
Notes	42

## Forward

The Wessex Mental Health, Dementia and Neurological Conditions Network is committed to supporting a collaborative approach to innovating, designing and delivering mental health, dementia and neurological services across Wessex.

Networks are uniquely positioned to bring together those who commission, provide and support services, providing a neutral and equitable platform where challenges and opportunities can be explored, and solutions planned. Wider understanding of system pressures and policy drivers can be shared whilst continuing to work with stakeholders to ensure that patient outcomes and experience remain a priority.

An accurate and timely diagnosis of dementia can ensure appropriate post diagnostic care and improved quality of life for people and their families. The Network viewed diagnostic brain imaging use from the perspectives of time to diagnosis and delivery of accurate diagnosis.

View seeking of imaging practice has been analysed to highlight evidencebased decision-making taking place in Wessex, and the development of dementia imaging services.

### Thank you



Dr Chris Kipps Clinical Director



Dr Denise Cope Clinical Director



Rachel Chappell Quality Improvement Lead

## **Executive Summary**

Brain imaging is an important, and often crucial part of the diagnostic pathway for dementia, yet there has been little focus on this aspect of service delivery. Anecdotal reports suggest high variability in the requesting and reporting of dementia diagnostic images. With a push to diagnose early, and accurately, it is important that we better understand factors that influence this aspect of the dementia pathway.

Defining the extent of dementia diagnostic brain imaging is challenging, and no publicly available dataset exist with this information. Data on overall levels of brain imaging do not define the proportion that is directly referable to dementia diagnosis. Complicating matters, structural brain imaging (CT, MRI) is used for a variety of non-dementia purposes, and functional imaging modalities (SPECT, DaTScan and PET) are not requested in the majority of people being investigated for dementia. We know, however, that overall imaging demand for brain imaging is broadly similar when comparing the Wessex region with national demand. In the Wessex region, nearly 25,000 people have been diagnosed with dementia and each year, a little over 10,000 people are newly diagnosed with forms of dementia.

In order to understand the dementia pathway and decision-making with respect to imaging, we surveyed psychiatrists across the Wessex region for their views. Nearly half of the referrers (48%) requested brain imaging on 90-100% of their patients, and over three quarters did the same for 75% of patients. We estimate that this equates to an imaging cost of between £668,000 and £861,000 per annum. This does not take into account more complex imaging modalities that may occur later in the pathway to further support diagnosis, and define dementia diagnosis subtype as recommended in NICE guidance (2018). Furthermore, this cost does not include scans performed for people with suspected dementia where dementia was ultimately not diagnosed, and therefore not registered in dementia registers.

A number of decisions are made with respect to imaging by clinicians. In some cases, more than one scan is requested; clinicians responded that this was largely to address diagnostic uncertainty, but also to evaluate progression of symptoms. Relatively few individuals would be referred for a repeat scan of the same modality with clinicians preferring to use a second modality to address issues of diagnostic uncertainty.

Imaging modality use varied, with the majority of referrers using CT scanning, and a high proportion requesting MRI, both forms of imaging that image brain structure. Functional imaging, assessing brain function, (SPECT, PET, DaTScan) was far less frequently requested, highlighting perhaps regional variation in availability, but also the nature of these modalities in offering second-line diagnostic support when initial (structural) imaging modalities are unable to resolve diagnostic uncertainty.

Referrers had quite nuanced reasons for selecting different modalities and making decisions that conform to NICE guidance (2018). Structural imaging (CT, MRI) was primarily used to rule out co-occurring pathology that may mimic dementia, whilst all modalities were used by referrers to support confirmation of a diagnosis. Subtype diagnosis was also supported by the use of all modalities, but particularly functional imaging (SPECT and DaTScans). Interestingly, referrers highlighted the importance of imaging in supporting patient understanding and acceptance of the diagnosis. In general patient expectation was felt to be strongest for the most widely known modalities (CT and MRI). The role of imaging in aiding care planning was noted, particularly for SPECT and DaTScans which have a particular role in defining dementia subtype.

Where dementia diagnosis was already clear, or where there were particular individual factors that limited particular use of imaging, this was either appropriately not performed, or the choice of imaging modality was altered.

The waiting time for scans to be performed is consistently longer in Wessex compared with national averages and is seen for all modalities other than PET imaging. When reports are received, referrers clearly found these useful, with some modality-specific variation. This may reflect the particular reasons for performing the scan: over 85% of referrers found functional imaging using SPECT and DaTScan imaging to be useful, with the highest proportion of 'very useful' responses across all modalities. These modalities are often used to detect dementia when clinical uncertainty remains after other modalities have been performed, and are useful for defining dementia subtypes which may be of particular clinical importance.

Dementia imaging reports could be more useful to referrers. When asked, they requested structured reporting of scans, focusing on specific features relevant to dementia diagnosis. For referrers, the detail is important, and the use of recognised rating scales was requested within imaging reports. Referrers, however, also wanted an opinion from reporters on the likelihood of dementia based on the imaging appearances.

Ultimately, the provision of a diagnosis of dementia should enable delivery of post-diagnostic care. Clinicians across the region felt that a confirmed diagnosis, including the dementia subtype had a substantial impact on post-diagnostic care. It was felt that dementia diagnosis had improved enormously over the past 20 years, at least in part due to improved options for brain imaging. Similarly, opinion was expressed that an evidence-based pathway for brain imaging in cognitive disorder would be very helpful to enable a better understanding of the value and limitations of each type of imaging. This would enable service to develop a more consistent, fair and cost-effective approach to requesting scans.

Dementia diagnostic imaging is important to dementia clinicians, they value it within diagnostic pathways, and request it in accordance with recommended guidelines (NICE, 2018). A scan adds weight to the clinical diagnosis of dementia, and helps address the likely cause. There is a significant cost associated with provision of imaging, and while referrers make judgements as to when this should be requested, improvements to the diagnostic algorithms would be helpful, particularly the sequencing of dementia imaging investigations in more complex cases. Similarly, quality improvements in reporting standards would assist clinicians to be more confident about their diagnostic decisions.

## Stakeholders

The Clinical Network has worked with the following stakeholders in the production of this report.

- Wessex CCGs covering both Hampshire and Isle of Wight and Dorset STPs
- Wessex memory assessment services (Southern Health Foundation Trust, Dorset Hospital University Foundation Trust, Isle of Wight Trust)
- Wessex Neurological Centre and services
- Wessex imaging providers (University Hospital Southampton, Hampshire Hospitals Foundation Trust, Queen Alexandria Portsmouth, Royal Bournemouth Hospital, Poole Hospital, Dorset County Hospital, Isle of Wight Trust)



## Who should read this report?

The Clinical Network operates across Wessex leading quality improvement and service transformation projects to improve patient experience and outcomes. As part of a whole system approach we work along clinical pathways and across organisational boundaries. Our range of stakeholders each have differing roles and responsibilities, and will each benefit differently from this report as indicated below.

### Commissioners

- Understand where in the dementia pathway brain scans are being requested
- Understand why scans are useful in diagnosis sub type
- Understand costs associated with dementia diagnostic imaging
- Understand the brain imaging required in an changing population?

### Referrers

- Understand when brain scanning is useful in your dementia diagnosis pathway
- Understand why scans are useful in making a dementia diagnosis sub type
- Understand the reasons not to scan
- Understand the impact of dementia sub type on your care plan

### **Imaging services**

- Understand volume of brain scanning
- Understand waiting times for brain scanning
- Consider activity data quality

### Image reporters

- Understand why people are being referred for brain imaging and at what stage in their dementia diagnosis
- Know what information will be useful to the referrer, why they need it and what they will do with it
- Consider other information that you could share with the referrer?

### **NHS system**

- Understand how linking data along pathways can improve quality of care.
- Understand the staging of investigations, access and waits on the dementia pathway
- Understand the costs of diagnosis in the dementia pathway as we have an increasingly older population and drive for early diagnosis requiring more scans in number and complexity.
- Use the findings to develop better guidance to improve dementia diagnosis pathways
- Create system links eg capacity modelling, waiting times, diagnosis rates, research themes

## Introduction

Attention on dementia care has recently been highlighted through several key national initiatives.

- Prime Minister's Challenge 2020 on Dementia stating that all people should have equal access to assessment for dementia with appropriate post diagnostic support
- NHS Five Year Forward View and planning guidance which mandates
  - maintenance of the diagnosis rate for dementia of two thirds underlying prevalence for the condition, and
  - improvements in the quality of post-diagnosis treatment and support
- NHS 10 Year Plan<sup>1</sup> which builds on these emphasising that dementia remains one of the top five causes of early death for the people of England and that further work is required.

### 'People are now living far longer, but extra years of life are not always spent in good health. They are more likely to live with multiple long-term conditions, or live into old age with frailty or dementia'

'We will go further in improving the care we provide to people with dementia and delirium, whether they are in hospital or at home.'

This Long Term Plan therefore sets out clear and costed improvement priorities for the biggest killers and disablers of our population..... confirm that the Plan needs to stick with and make further advances on our current improvement agenda for cancer, mental health, multimorbidity and healthy ageing including dementia...

On this basis, it is important that we continue to review the dementia care pathway, to support efforts to deliver a timely and accurate diagnosis to inform the provision of appropriate post diagnostic care. The Well Pathway for Dementia clearly identifies five stages of the pathway.

<sup>1</sup> The NHS Long Term Plan, 2019

### Figure 1: The Well Pathway for Dementia, NHS England



Brain imaging (or scanning) is a key diagnostic activity within the dementia diagnosis pathway. Brain images, acquired with techniques such as Computerized Axial Tomography (CT) or Magnetic Resonance imaging (MRI) provide information on brain structure, and can delineate brain neurodegeneration and rule out various non-neurodegenerative causes. Other forms of imaging including single-photon emission computed tomography (SPECT), positron emission tomography (PET) and dopamine transporter imaging (DaTScan) can further define the presence of neurodegeneration, and support subtype differentiation within the diagnostic pathway (see Appendix 1).

The use of imaging to support diagnosis is a prominent part of the updated guidance issued by NICE<sup>2</sup> in June 2018, and emphasise the need for imaging to support diagnosis of dementia, and definition of dementia subtype. A range of modalities are recommended for use: local referrers have indicated that they request scans for the majority of their patients.

Nationally, some evidence has been presented of significant variation in dementia imaging protocols at local level. A Wessex research study<sup>3</sup> identified significant variation in confidence of referrer diagnosis (pre and post reporting) and variation in reporting.

<sup>2</sup> NICE guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers <sup>3</sup> The impact of perfusion SPECT imaging on clinician diagnostic confidence in dementia, Prosser, Tossici-Bolt and Kipps, 2019 (in submission)

## Aims

This review of diagnostic imaging for dementia was undertaken with the following aims:

- Understand current demand, capacity and variation in imaging as part of the Wessex dementia care pathway
- Understand imaging best practice considering
  - NICE guidelines,
  - referral practice
  - cost and quality of imaging
  - reporting practice
- Identify opportunities and challenges for improvement in the local systems
- Disseminate recommendations across Wessex commissioners and providers



## Methods

The project concentrated on three lines of enquiry: an online survey; data review from national datasets; review of NICE guidelines.

### **Online survey**

An online survey was sent to dementia imaging requesting clinicians across Wessex. This primarily included psychiatrists who order the bulk of dementia diagnostic scans via Memory Clinics. The survey was sent to all psychiatrists in the Wessex region including senior trainees. The survey invited feedback on referring habits, the usefulness of imaging in diagnosis, and the impact on ongoing patient care. The survey was sent to 95 referrers with responses from 21 including

- Southern Health Foundation Trust (12)
- Dorset Healthcare Trust (6)
- Solent Trust (3).

### Imaging activity data review and data limitations

Data is collected in the NHS for a variety of purposes and often held as part of standard datasets. Data in each dataset may become available at different times and may hold similar but not identical data.

A review of available data was undertaken including:

- National Diagnostic Imaging Dataset (DID) set, NHS Digital<sup>4</sup>
- Public Health England ('Fingertips') profiles<sup>5</sup>
- NHS England Mental Health Services Data Set (MHSDS)<sup>6</sup>

The Diagnostic Imaging Dataset holds detailed information on all diagnostic imaging carried out on NHS patients, extracted from local Radiology Information Systems. This was originally designed as a tool to understand cancer diagnostic activity and waiting times. As such, assumptions and caveats should be applied when using this data in relation to imaging as part of dementia diagnosis; not all brain scans are for dementia diagnostic use.

Data released by Public Health England is based on GP Quality Outcome Framework (QOF) and Office of National Statistics (ONS) data.

The Dementia Diagnosis Rate is a measured target for CCGs in England and data is reported from GP practices to NHS England on a monthly basis via the Mental Health Services Data Set.

Drawing absolute comparisons from this range of data sources may not be possible, however, they provide useful insight into trends and give suitable benchmarks from which overall conclusions can be drawn.

### **Review of NICE guidelines**

The NICE guidelines for dementia assessment were revised in June 2018<sup>7</sup>. These were used as a comparator for the findings from data review and survey.

<sup>5</sup> https://fingertips.phe.org.uk/

<sup>&</sup>lt;sup>4</sup> https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/diagnostic-imaging-data-set

 $<sup>^{6}</sup> https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-sets/data-sets/mental-health-services-data-sets/data-sets/data-sets/mental-health-services-data-sets/data-sets/data-sets/mental-health-services-data-sets/data-sets/data-sets/mental-health-services-data-sets/data-sets$ 

<sup>&</sup>lt;sup>7</sup> https://www.nice.org.uk/guidance/ng97

## **Review Findings**

The findings of this review are reported as answers to a series of questions framed around the benefits of dementia diagnostic imaging:

- Is brain imaging activity an adequate proxy for assessing dementia imaging activity?
- Is imaging useful in the dementia diagnostic pathway?
- Who requests the majority of dementia brain imaging?
- What level of dementia brain imaging diagnostic activity is being performed in Wessex?
- What cost is associated with dementia diagnostic imaging, how many diagnoses are we making, and is there evidence of multiple imaging modalities (or repeat imaging) being used in the same individual?
- What type of scans are requested, and what is the rationale for these requests?
- What are the waiting times for scans and reports, how useful are they to the referrer, and what impact do these have on patient care?

# Scanning activity data as a proxy measure for diagnostic dementia imaging

The national imaging data set does not record the purpose of requested scans and cannot be linked directly to a care pathway or diagnosis. It is possible to filter imaging data to identify scan types, referrers and locations. The table below shows the filters selected for this project and the rationale behind them. This provides a useful proxy of imaging related to dementia diagnosis but not an exact figure. For example, a CT scan for 'Head', 'aged 65+' may be for a traumatic injury or for possible dementia.

The data in this report was provided from NHS Digital in accordance with the iView terms and conditions for data sharing<sup>8</sup>. In accordance with the data suppression rules all figures in the following report below 3 are shown as \* and all other figures are rounded to the nearest 5. Due to data suppression, totals may not match the sum of rows or columns.

### Table 1: Filters used to extract scanning activity data

Data	Filter	Rationale
Age	65 +	The majority (but not all) of dementia diagnoses are made in people who are aged 65+. The national dementia diagnosis rate target is based on diagnoses for people age 65+.
Date range	2017-2018	This is the most recently released, quality assured dataset available
Exam region	Head structure (body structure) (69536005)	Dementia is an organic condition of the brain and this will be reflected in requests for head scans
Modality	Computerized axial tomography (procedure 77477000) Magnetic resonance imaging (procedure 113091000) Nuclear medicine procedure (procedure 371572003) Positron emission tomography (procedure 82918005) Single photon emission computerized tomography (procedure 105371005)	These scanning modalities at most useful in a dementia diagnosis
Submitter organisations	Dorset County Hospital NHS Foundation Trust (RBD), Hampshire Hospitals NHS Foundation Trust (RN5), Isle Of Wight NHS Trust (R1F), Poole Hospital NHS Foundation Trust (RD3), Portsmouth Hospitals NHS Trust (RHU), The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust (RDZ), University Hospital Southampton NHS Foundation Trust (RHM)	Providers of imaging services in Wessex

### The Wessex population

Wessex covers the geographical areas of Dorset and Hampshire and the Isle of Wight. The tables below show Wessex population information relevant to the dementia pathway. The prevalence of dementia is approximately 38,000 people across the Wessex region, while the dementia register for people aged 65 years and over is around 24,500 individuals.

#### Table 2: Dementia diagnosis data as at July 2019

Area/STP	Achievement DDR rate (March 2019)	Sum of dementia registers (65+)	Estimated dementia prevalence CFAS II (65+)	
National	68.7	453,840	668,177	
Dorset STP	61.7%	8,324	13,408	
Hampshire, Isle of Wight STP	65.4%	16,250	24,856	
Wessex	-	24,574	38,264	

(National performance dataset March 2019)

Area/STP	Achievement DDR rate (Mar 2018)	Sum of dementia registers (65+)	Estimated dementia prevalence CFAS II (65+)	
National	67.5	435,574	645,507	
Dorset	61.4%	8,045	13,101	
Hampshire, Isle of Wight	64.9%	15,586	24,029	
Wessex	-	23,631	37,130	

#### Table 3: Dementia diagnosis data as at March 2018 (for comparison with available imaging data)

(National performance dataset March 2018)

## Table 4: Benchmarking data for dementia populations March 18 (for comparison with available imaging data)

Area/STP	Dementia prevalence (65+)	Newly registered dementias in year (65+)	Newly registered diagnoses as % of recorded prevalence	Deaths from dementia in year aged 65+	Deaths as % of recorded prevalence
National	448,348	112,407	25.2%	91,906	20.5%
Dorset	8,205	2,171	26.4%	1,844	22.5%
Hampshire, Isle of Wight	15,901	3,952	24.6%	3,589	22.6%
Wessex	24,106	6,123	25.5%	5,433	22.5%

Public Health England fingertips 2017-2018

In Wessex and Nationally, 20-25% of diagnoses are new each year, with a similar proportion being newly registered in Hampshire, Isle of Wight STP (24.6%; 3,952 people) and Dorset STP (26.4%; 2,171 people). Each year, this equates to 6,123 people (aged 65 years and above) being given a new diagnosis of dementia.

### Is imaging useful in the dementia pathway?

NICE guidance (NICE, Dementia Guideline, 2018<sup>9</sup>) recommends that structural imaging should be offered to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established, and the subtype is clear.

In the survey of referrers 20/21 responders (95%) said that they routinely referred people for imaging as part of their usual diagnostic process. Referrers were asked to further estimate of the proportion of their patient group they referred.

<sup>9</sup> https://www.nice.org.uk/guidance/ng97

## Figure 2: What % of your patients do you refer for brain imaging as part of the dementia diagnosis process?



#### **Key observations:**

- 47.7 % of referrers referred 90 to 100% of their patients for a scan as part of the diagnostic pathway
- 4.8% of referrers referred less than 10% of their patients for a scan.

This suggests that brain imaging is routinely offered to patients as a part of the dementia diagnostic pathway in line with NICE 2018 guidelines.

### Who is requesting imaging?

Scan requests can be made by a range of professional groups according to local policy. The table of data below shows request activity by professional group for the Wessex region.

Modality	Consultant	Dentist	GP	Nurse	Physio	Other Health Professionals	Unknown	Total
СТ	37,160	5	580	110		*	3,415	41,270
MRI	13,440	30	195	5			1,060	14,730
Nuc Med	140		*				5	145
PET	190						15	205
SPECT	220		10				5	235
Total (%)	51,150 (90.4%)	35 (0.1%)	785 1.4%	115 0.2 <i>%</i>	0	*	4,500 (8.0%)	56,585 (100%)

Table 5: Scans requested by professional groups in Wessex

(Diagnostic Imaging Dataset, 17/18, head structure, 65+)

#### **Key observations**

- Brain imaging is primarily a consultant-lead process (90.4%)
- GP brain imaging requests comprise only 1.4% of scans

### What is the level of imaging activity in Wessex?

Wessex and National imaging activity 2017-18 is shown in the table below. Scans of the head for people aged 65+ account for 9.0% of Wessex scans and 8.5% of the national scans.

It should be noted that the regional dataset analysis is not the ideal proxy for estimating the proportion of individuals with a scan specifically for dementia, or for estimating the proportion of people with suspected dementia offered a diagnostic scan. However comparisons can be drawn.

## Body Region Wessex Wessex body region as Natio

Table 6: Number of scans undertaken in Wessex and Nationally

Body Region	Wessex Total	Wessex body region as % total scans	National Total	National body scan region as % total scans
Abdominal structure	58,105	8.3%	1,291,670	8.1%
Head structure	62,865	9.0%	1,357,130	8.5%
Limb structure	134,200	19.3%	3,130,695	19.7%
Neck structure	18,265	2.6%	418,145	2.6%
None	135,400	19.4%	3,291,745	20.7%
Pelvic structure	46,105	6.6%	1,057,890	6.7%
Thoracic structure	241,410	34.7%	5,360,385	33.7%
Total	696,350	100.0%	15,907,660	100.0%

(Diagnostic Imaging Dataset, 17/18, head structure, 65+)

#### **Key observations**

- Head scans account for 9% of the total scans in Wessex compared to 8.5% nationally
- Importantly, the total scan count far exceeds the number of individuals being diagnosed with dementia each year (62,865 scans versus 6,123 diagnoses)
  - even allowing for some individuals having more than one scan as part of the diagnostic processes, the non-dementia diagnostic brain imaging far exceeds the dementia scans
  - the data do not allow calculations on the number of people who had dementia diagnostic imaging in whom the diagnosis was of *no dementia* (and who therefore do not appear within the dementia diagnosis figures)

### New diagnoses of Dementia

Imaging plays a key role in supporting new diagnoses of dementia and identifying dementia sub types. Public Health England published an experimental indicator for 17/18 described as the Rate of newly diagnosed dementia registrations. This is calculated from new registrations eligible for an in year QOF payment and is used as a proxy for incidence of dementia.

Table 7: New diagnoses of dementia recorded in Wessex and Nationally

Area/STP	Dementia prevalence (65+)	Newly registered dementias in year (65+)	Newly registered as % of recorded prevalence
National	448,348	112,407	25.2%
Dorset	8,205	2,171	26.4%
Hampshire, Isle of Wight	15,901	3,952	24.6%
Wessex	24,106	6,123	25.5%

Public Health England fingertips 2017/18

#### **Key observations**

- Nationally 112,407 new recordings of dementia diagnosis in 17/18
- In Wessex 6,123 new diagnoses of dementia in 17/18
- At National, STP and Wessex level, new diagnoses are within 1.2% of each other.

### Cost of scanning for new diagnoses

Across England imaging may be commissioned on a PbR (Payment by Results) basis or as part of a block contract. The table in Appendix 2 shows the scanning national tariff, which may be useful in approximating a diagnostic imaging cost for new diagnosis of dementia across Wessex.

Dementia incidence can be used to estimate approximate cost ranges of imaging based on a series of assumptions.

Assumptions used in cost estimates (referenced in table below)

- 1) 10% of patients are **NOT** referred for a scan
- 2) 90% of patients are referred for a scan where
  - a. 70% of patients are referred for EITHER a CT or MRI scan (on a range of percent splits)
  - b. 20% of patients will have BOTH a CT and MRI scan
- 3) All referrers refer a similar number of patients overall for diagnostic imaging

Dementia scan modalities and cost

- CT (1 area, no contrast) @ total cost of £91
- MRI (1 area, no contrast) @ total cost of £136

### Table 8: Estimations of scanning costs

No of new diagnoses (Wessex)	Assumption group	% having scan	No of scans in scan category	Ratio of CT to MRI	Total cost group	Total cost (scan assumption ratio plus two scans)					
6123	No scan (1)	10	612								
	One scan (2a) 70 (CT or MRI)	70	4286	100% CT	£390,035.10	£668,019.30					
				75% CT 25% MRI	£438,253.73	£716,237.93					
				50% CT 50% MRI	£486,472.35	£764,456.55					
									25% CT 75% MRI	£534,690.98	£812,675.18
				100% MRI	£582,909.60	£860,893.80					
	Two scans (2b) (CT and MRI)	20	1225		£277,984.20						

No of new diagnoses (Dorset)	Assumption group	% having scan	No of scans in scan category	Ratio of CT to MRI	Total cost group	Total cost (scan assumption ratio plus two scans)
2171	No scan (1)	10	217			
	One scan (2a)	70	1520	100% CT	£38,292.70	£ 236,856.10
	(CT or MRI)			75% CT 25% MRI	£155,389.33	£253,952.73
				50% CT 50% MRI	£172,485.95	£271,049.35
			25% CT 75% MRI	£189,582.58	£288,145.98	
				100% MRI	£206,679.20	£305,242.60
	Two scans (2b) (CT and MRI)	20	434		£98,563.40	

No of new diagnoses (HIoW)	Assumption group	% having scan	No of scans in scan category	Ratio of CT to MRI	Total cost group	Total cost (scan assumption ratio plus two scans)	
3952	No scan (1)	10	395				
	One scan (2a) (CT or MRI)         70         2766           Two scans (2b) (CT and MRI)         20         790	70	2766	100% CT	£251,742.40	£431,163.20	
				75% CT 25% MRI	£282,864.40	£462,285.20	
			50% CT 50% MRI	£313,986.40	£493,407.20		
					25% CT 75% MRI	£345,108.40	£524,529.20
			100% MRI	£376,230.40	£555,651.20		
		790		£179,420.80			

(National tariff workbook – planning process for 2017/18)

### Multiple imaging?

Brain imaging is a valuable step in making a diagnosis but there may be occasions when a single scan does not provide sufficient information to confidently define a dementia and/or a dementia subtype.

Referrers were asked to estimate the proportion of patients they referred for more than one scan, and whether scans were the same, or different, modalities.

## Table 9: What % of patients have more than one scan where the modality is the <u>SAME</u> (e.g. CT followed by CT)

% of patients referred	>90%	75%	50%	25%	10%	<10%
No of responses	0	0	1	2	7	10

## Table 10: What % of patients have more than one scan where the modality is <u>DIFFERENT</u> (e.g. CT followed by MRI)

% of patients referred	>90%	75%	50%	25%	10%	<10%
No of responses	0	0	4	5	7	4

- Referrers seldom refer their patients for repeat scans of the same modality (10% of the time, or less)
- Where repeat scans are requested these are more likely to be a <u>different</u> modality (up to 50% of the times with repeat scans)

Refers were then asked to share in their own words, the reasoning for multiple scan requests

#### Table 11: Multiple scan rationale

Rationale for multiple scans	Number of responses
Progression of symptoms or condition	7 (30%)
Diagnostic uncertainty	13 (54%)
Sub type specification	2 (8%)
Other	2 (8%)
Total responses	24

Overall, repeat scanning is not routine. Where repeats are requested this is either for increased sensitivity or a different purpose.

### Imaging: what modality types are requested?

Referrers were asked which of the available imaging modalities they routinely used for dementia diagnosis (for list see Appendix 1).

## Figure 3: Which imaging modalities do you routinely refer people to as part of the dementia pathway?



**Key observations** 

- Referrers most frequently request CT and MRI scanning. This is confirmed by imaging activity data where CT and MRI account for 99% of head images
- The lower percentages for SPECT, DAT and FDG-PET may be due to difficulty in identifying specific dementia imaging from the National datasets or these may be less commonly provided modalities

### Rationale for choice of imaging modality?

Referrers were asked what factors they consider when requesting a scan for an individual patient and the specific circumstances why they might not request a scan.



### Figure 4: Comparison of 'Why do you refer?' responses for each specific scan type

#### **Key observations**

- CT and MRI imaging are most useful in ruling out other diagnostic concerns, however they were felt to be relatively less useful at confirming a dementia diagnosis
- All modalities were felt to support dementia sub type diagnosis
- Brain diagnostic imaging was an important factor in patient experience and meeting patient expectation
- Functional imaging (SPECT, DAT) were particularly useful in aiding care planning
- Lack of availability of Amyloid-PET limits referral for this imaging modality

### Figure 5: Comparison of 'Why do you NOT refer?' responses for each specific scan type



#### **Key observations**

- Reasons not to request a scan are in line with NICE guidelines
- Referrers also consider patient preferences and practical concerns.

A range of rationale are used in image requests to reflect both clinical decision making and patient experience. The rationales given are in line with NCE guidelines.

Referrers were also given a free text opportunity to offer other rationale for their decision-making process. These are shown below

### Table 12: Other rationale for scan decision making

Scan type	Other reasons for referring	Other reasons for NOT referring
СТ	<ul> <li>To rule out any other causes of cognitive impairment.</li> <li>NICE clinical pathways suggest we should offer neuroimaging all cases suspected of dementia</li> <li>To support the clinical diagnosis of dementia rather than confirm diagnosis</li> <li>At [specific] hospital MRI requests often changed to CT scan.</li> <li>On admission unwell patients may be CT scanned to rule out other concerns, especially if an unusual presentation</li> </ul>	• Clear clinical picture of Alzheimer's dementia at the time of initial assessment
MRI	<ul> <li>Early onset</li> <li>Inconclusive CT report</li> <li>Strong fronto-temporal clinical presentation from the beginning</li> <li>In younger patients</li> <li>In patients with atypical or complex presentations</li> </ul>	<ul> <li>Contraindicated- medical or metal work in patient, being unable to lie flat or tolerate enclosed scan,</li> <li>Cost</li> <li>MRI only indicated for patients under 70 or where advised by a radiologist or as part of FTD diagnosis</li> </ul>
SPECT	<ul> <li>Unusual/atypical presentations where structural scans have been unremarkable</li> <li>Younger patients ie &lt;65</li> <li>Uncertain disease process and unclear diagnosis based on symptoms</li> <li>To make decisions about appropriate medications and prognosis</li> </ul>	<ul> <li>Portsmouth offers PET-CT as an alternative to SPECT so usually don't refer to Southampton specifically for SPECT</li> <li>When FDG-PET is unavailable</li> <li>Duration of the process</li> <li>Stopped requesting HMPAO scans after wider availability of FDG-PET, following advice by local nuclear medicine department</li> <li>NICE guidelines say that we use SPECT only if FDG-PET is unavailable</li> </ul>
DAT	<ul><li>Lewy Body Dementia</li><li>To avoid use of antipsychotics in future</li></ul>	<ul> <li>Ability of patient to attend and cooperate with scan is important as takes 3-4 hours for appointment and they need someone to accompany them.</li> <li>Only refer if LBD suspected</li> <li>It may be useful but is complex for patients and not as useful as a well taken history</li> </ul>
FGD-PET	• Understand this is useful as a research tool in dementia	<ul> <li>I'm not familiar with this type of scanning.</li> <li>Exclusion criteria for the scan</li> <li>Rarely refer as I have less experience of these than SPECT scans &amp; what I have experienced has not been as helpful</li> <li>Available other scans</li> <li>When patient also suffers from uncontrolled diabetes</li> <li>Not sure how beneficial it is for diagnosis</li> </ul>

<ul> <li>No immediate local availability and HMPAO-SPECT available locally</li> <li>Variation in reporting</li> <li>Would need more education to be confident in its proper use.</li> <li>I do not refer for FDG-PET brain scanning</li> <li>I do not refer for FDG-PET as my understanding is that this is not available in our region and we have access SPECT instead.</li> <li>Amyloid PET</li> <li>Haven't used this modality or is not available locally</li> <li>To rule out Alzheimer's disease with a negative result</li> <li>No tavailable as far as I understand</li> <li>Lack of accuracy of the test (with significant false positives);</li> <li>Cost</li> <li>Have never referred and not aware where this is available outside research projects</li> <li>Also, presence of Amyloid does not erupte to</li> </ul>			
Amyloid PET       • Haven't used this modality or is not available locally       • Not available as far as I understand         • To rule out Alzheimer's disease with a negative result       • Not available as far as I understand         • Lack of accuracy of the test (with significant false positives);       • Cost         • Have never referred and not aware where this is available outside research projects       • Also, presence of Amyloid, does not equate to			<ul> <li>No immediate local availability and HMPAO-SPECT available locally</li> <li>Variation in reporting</li> <li>Would need more education to be confident in its proper use.</li> <li>I do not refer for FDG-PET brain scanning</li> <li>I do not refer for FDG-PET as my understanding is that this is not available in our region and we have</li> </ul>
<ul> <li>Amyloid PET</li> <li>Haven't used this modality or is not available locally</li> <li>To rule out Alzheimer's disease with a negative result</li> <li>Not available as far as I understand</li> <li>Lack of accuracy of the test (with significant false positives);</li> <li>Cost</li> <li>Have never referred and not aware where this is available outside research projects</li> <li>Also, presence of Amyloid, does not equate to</li> </ul>			access SPECT instead.
* Also, presence of Antyloid, does not equate to	Amyloid PET	<ul> <li>Haven't used this modality or is not available locally</li> <li>To rule out Alzheimer's disease with a negative result</li> </ul>	<ul> <li>Not available as far as I understand</li> <li>Lack of accuracy of the test (with significant false positives);</li> <li>Cost</li> <li>Have never referred and not aware where this is available outside research projects</li> <li>Also, presence of Amyloid, does not equate to</li> </ul>

### Scan and report waiting times?

Waiting time data from the GP requesting a scan to receiving a scan report can broken down into key steps as shown in the following diagram.

### Figure 6: Diagram of steps in the scan requested to report issued process



The average wait in days (total days including weekend days) for each step and for the whole pathway is shown for head scans for those aged 65 and over for the given modalities.

Due to the data supression rules of small numbers and rounding, the individual steps may not be shown and may not add up to the total waiting time. The total time should be considered the more accurate value however the breakdown is also useful.

Average wait in days per request at each stage 4 3 1 2 Request received to Total time from request Scan requested to Scan occurs to report request received issued Scan occurs to report National Wessex National Wessex National Wessex National Wessex СТ 0.25 0.66 4.77 4.26 1.19 1.45 5.94 6.66 MRI 2.05 18.57 35.88 37.95 5.73 6.84 43.06 59.48 Nuc Med 35.66 5.70 40.42 68.03 1.29 1.33 65.97 4.61 PET 26.40 1.23 3.41 2.34 26.71 12.89 SPECT 1.05 1.21 39.13 70.83 8.87 15.31 47.72 86.60

### Table 13: Average waiting time in days for steps identified

(Diagnostic Imaging Dataset, 17/18, head structure, 65+)

### Figure 7: Average wait in days total from 'Test requested' to 'Report issued' (Step 4)







#### **Key observations**

- With the exception of PET scanning, waiting times for all other imaging modalities are longer in Wessex than seen nationally
- Request received to scan performed interval (Step 2) seems to account for the majority of increased waiting times compared to national waits, and is most noticeable for MRI requests
- SPECT scanning wait times are longest at 86.9 days (12.4 weeeks) compared to national waiting time of 47.72 days (6.8 weeks). This is may be driven primarily by long intervals from request to scanning due to need to order radiotracer or may be related to service capacity.

### How useful are brain imaging diagnostic reports?

Imaging reports are provided by radiologists to share imaging findings with the referrer. We asked referrers how useful they found the information in imaging reports.



### Figure 9: Comparison of 'Are the reports useful?' question for each specific scan type

#### **Key observations**

• The majority of referrers report find scan reports very or mostly useful, however this varies by modality and availability.

Referrers were also asked how the reports could be made more useful to them. A total of 57 comments were received. These have been themed and are shown below. Referrers requested more information in reports on common imaging features such as atrophy and white matter lesions, validated metrics including MTA, Fazekas and Koedam scores, and greater level of detail on images. An opinion on the likelihood of neurodegeneration and specific recommendations were further features requested in imaging reports.

#### Table 14: Themed comments on reports

Comment theme	Total
Provision of details on common imaging metrics (including MTA, Fazekas and Koedam scores)	16
Details on imaging features (including global atrophy, white matter lesions and vascular disease	13
Structure of reporting (format and depth of details)	13
Opinion on likelihood of neuro degeneration and recommendations	11
Availability of actual images	2
General /other	2
Total	57

### What is the impact of imaging on post diagnostic care?

Referrers were asked to indicate on a scale of 1 to 100 how much having a confirmed diagnosis (including subtype) impacted on post diagnostic care provided.

#### **Key observations**

• Almost all referrers felt that having a confirmed diagnosis impacted on the provision of post diagnostic care, with an average score of 70 (where 0 represented limited impact, and 100 a significant impact on care).

Figure 10: How much does having a confirmed diagnosis, including sub type, impact on the post diagnostic care you provide? Mark on scale where 0 = Limited impact on care and 100 = significant impact on care



(N=20) Average score = 70

### Final thoughts from referrers

Free text responses were sought at the conclusion of the survey for additional information that referrers felt was pertinent, but had not been covered in the previous questions. A total of 12 referrers responded with a total of 16 comments.

## Question: Do you have any other comments regarding the use of diagnostic imaging in Wessex as part of the dementia diagnosis pathway?

- Service is excellent.
- Opinions are objective and helpful
- Reporting could be less dependent on the reporter. More structure to the report. I have more confidence in some radiologists, and this should not be the case
- No
- Widely variable practice but at least now majority of clinicians request scanning for majority (over 90%) of patients referred for suspected dementia if they haven't already had a scan within last one year
- None
- The waiting times vary enormously between WNC and local hospitals which is good for the patients in the New Forest as that can be done much quicker in Lymington
- The quality of the functional imaging reports is very good, thank you
- Diagnosis has improved enormously in last 20 years in part due to improved scanning options
- In Portsmouth it is almost impossible to get MRI unless patient young or via a neurologist
- We have the dilemma that a PET scan can be obtained quickly but clinicians have some concerns about the reporting
- I would send all patients requiring a functional scan for a SPECT in preference if it was not for some patients being put off by going to Southampton, the long wait for a scan and the sometimes long wait between scan and reporting
- An evidence-based pathway specifically for brain imaging in cognitive disorder would be very helpful to enable a better understanding of the value and limitations of each type of imaging. This would help us as a service to develop a more consistent, fair and cost effective approach to requesting scans (I'm aware that developing such a pathway is not straight forward!)
- The only scan which you can get within a few days is the PET scan, which is fantastic, but I am never certain I can trust the results
- I feel lucky to have the help of neuroradiology in SGH for my patients
- Let's not confuse dementia as disability of mental skills, with the cause of dementia. There is a risk of misdiagnosis if doctors think a scan is diagnostic. It's the history and cognitive testing that diagnose dementia and the scan that adds weight to the cause. Scans also have great value in the explanation to patients and family. Showing the scan can be very powerful

## Discussion

### When to scan and which modality?

Diagnosis of dementia should be based on presentation, clinical history and cognitive testing. Brain imaging also has a role to play and is recommended in NICE guidelines. NICE also notes that Alzheimer's disease should not be ruled out based solely on apparently normal results of CT or MRI scans.

The survey and activity data indicate that imaging is utilised in Wessex as a diagnostic tool alongside clinical history and presentation. The volume of our proxy imaging count (head structure, age 65+) is similar to national activity levels.

Imaging is mostly used as an aid to new diagnoses (or significant changes in presentation). Conversely imaging is not required in every case and patient expectations and experience is also considered in referral decisions.

A range of imaging modalities are available to referrers which appear to be understood and utilised to best effect. The rationale for selecting each modality appear to be in line with guidelines. Comments have been raised in this report and anecdotally that local imaging protocols alter requested MRI scans to CT scans. There may be an opportunity to change protocol where MRI is requested as part of a dementia pathway. Amyloid PET scanning is not routinely available and is currently research level use only.

### Why? and Why not?

Referrers make deliberate choices to scan, and do not do so when the benefit to the individual is perceived to be low. Structural imaging is frequently used to rule out non-dementia causes, in line with guidance. Functional imaging is used to subtype and confirm dementia diagnosis when structural imaging is unable to resolve the underlying cause of cognitive decline. A clear diagnosis of dementia and subtype is considered important and aids post diagnostic care.

### Waiting times

There is considerable variation between National and Wessex waiting times and differences in waiting time for each modality. The local knowledge of waiting time length may influence clinical decisions on image modality requested.

The key delay appears to be from the time the request is received to the time for the scan to take place. Factors affecting this could include availability of equipment, number of providers and workforce capacity although this was not directly assessed.

### Reporting

Imaging services are perceived as key partners in the dementia diagnosis pathway. Imaging reports contain valuable information for the referrer, particularly where neuro-radiologists (or reporters with special expertise in dementia). Reports could be improved to ensure that they provide sufficient structured information to allow the referrer to be confident about clinical decisions based on imaging reports. Referrers specifically wish to see reporters use validated imaging scales, describe pertinent features relevant to dementia, and to express an opinion on their significance (see Table 14).

### **Patient Experience and Outcomes**

Referrers are aware that brain images can be a powerful aid to share with individuals and families as part of the diagnostic process.



## Conclusions

Accurate timely diagnosis of dementia is important. Imaging is a key diagnosis tool enabling confirmation of diagnosis and clarity on dementia subtype. This becomes all the more important as we move to diagnose earlier in presentation. This in turn enables appropriate post diagnostic care and support to individuals and their families.

The referrer survey and activity data reviewed in the report demonstrate that:

- Scanning is valued and a range of imaging modalities are available and used
- Imaging is clearly an established part of pathway and referrers make decisions based on questions they want to answer
- Ruling out other (non-dementia) pathology, confirming dementia presence and subtype confirmation are important to referrers
- Structured reporting important along with standardised protocols may assist in improving the usefulness of imaging reports, and the decisions that are based on them; opinion on the likelihood of underlying neurodegeneration would also be helpful to referrers
- The imaging activity and therefore costs are a proxy figure, however with an ageing population and the need for earlier diagnosis it is unlikely that this cost will reduce
- Waiting times for imaging in Wessex are longer than those seen nationally; the reasons for this are unclear

## **Considerations for future work**

An evidence-based pathway specifically for brain imaging in cognitive disorder would be very helpful to enable a better understanding of the value and limitations of each type of imaging. This would help us as a service to develop a more consistent, fair and cost-effective approach to requesting scans

Survey respondent

This report provides an opportunity for system partners to work together to optimise dementia diagnosis through imaging. The following points could be considered as a basis for quality improvement activity.

- Develop diagnostic algorithms for dementia diagnostic imaging requesting
- Develop standardised requesting and reporting templates for dementia diagnostic scans
- Audit actual use of dementia imaging and map incremental value of diagnostic imaging in a variety of diagnostic circumstances
- Develop education packages to support best practice in the use of imaging to support dementia diagnosis

The Clinical Network will continue to host workshops and support system stakeholders in developing and delivering these aims.

## Appendices

### Appendix 1: Imaging types and descriptions

### **CT** scan

Full name: Computerised tomography

**Description:** Structural scan, multi slice x-ray producing detailed images of internal structures including organs, blood vessels and bones. Contrast can be used to identify tumors or inflammation but is not useful for identifying dementias.

Time: approx. less than 5 minutes scan time.

#### Useful in dementia pathway to:

- Exclude other pathologies
- Measure extent of cerebro-vascular disease and estimation of hippocampal atrophy (recognised biomarker for Alzheimer's disease)
- Positive response to any of the screening questions for normal pressure hydrocephalus, frontotemporal dementia or cerebrovascular disease.
- Meets MRI protocol but patient has contraindications for MRI see MRI section below
- History of cancer that could metastasise to the brain (would need contrast).

#### **Contra indications:**

• Radiation exposure – in older forms of dementia unlikely to be an issue. May be more of a concern with multiple scans if younger.

### **MRI scan**

Full name: Magnetic resonance imaging

**Description:** Structural scan using magnetic fields to produce detailed internal images

Time: approx. 15 to 90 minutes.

#### Useful in dementia pathway to:

- Detect regional loss of volume (atrophy)
- Detection of vascular pathology
- Atypical presentation and subtype definition
- Acute or rapidly progressive dementia
- Detection of alternative (non-neurodegenerative) causes of cognitive decline

#### **Contra indications:**

- Patient may feel claustrophobic, may be poorly tolerated by elderly patients
- Can be loud and requires patient to lie still for duration

### SPECT - (HMPAO brain scan)

Full name: Reduced perfusion on hexamethylpropyleneamine oxime (HMPAO) scans

**Description:** Functional scan which delineates blood flow to the brain, which decreases when there is regional brain dysfunction; uses a small amount of radioactive tracer

Time: approx. 25 minutes plus additional scanning time (90 minutes)

#### Useful in dementia pathway to:

- Detect neurodegeneration and confirmation of dementia diagnosis, particularly when structural imaging is equivocal or normal
- Dementia subtype differentiation, especially AD from FTD
- important in young onset dementia where there is more likely to be an unusual or atypical form of dementia present
- Where there is complex presentation which may be related to underlying mental health problems but where the clinician suspects that the underlying cause may be dementia
- Establish vascular pathology

#### Contra indications: none

### **FDG PET**

Full name: Positron emission tomography scan

**Description:** Functional scan producing detailed 3-dimensional images by detecting areas of lowered brain metabolism via use of radioactive tracer

Time: approx. 30 mins plus scanning time (90 minutes)

#### Useful in dementia pathway to:

- Subtype differentiation
- Confirmation of neurodegenerative disease

#### **Contra indications:**

• if a patient is diabetic this test becomes more difficult to interpret

### DAT

Full name: Dopaminergic single photon emission computed tomography scan

**Description:** Shows level of dopamine transporter function in brain using a small amount of an iodine based radioactive material. Dopamine is a brain neurotransmitter involved in movement which may decline in parkinsonian disorders including Parkinson's disease and Lewy Body disease.

Time: approx. 25 minutes.

#### Useful in dementia pathway to:

- Assessment in those with suspected Lewy Body dementia (a form of dementia associated with visual hallucinations, falls and enhanced susceptibility to neuroleptic medications)
- Differentiating between Alzheimer's Disease and Lewy Body dementia
- Differentiate between drug induced parkinsonism and neurodegenerative parkinsonian causes

#### **Contra indications:**

• Nil

### **Amyloid PET scanning**

Full name: Amyloid Positron Emission Tomography

**Description:** A form of PET scan where a radioligand with affinity for amyloid plaques within the brain is used to map the presence (or absence) of amyloid.

### Useful in dementia pathway to:

- Define neurodegeneration as being due to Alzheimer's disease
- For entry into clinical trials

Contra indications: Not routinely available in NHS England contract

### **Appendix 2: Scanning costs**

## Table 15: Costing data taken from National Tariff 17/18 published by NHS Improvement and NHS England

Scan	Scan Cost £	Report Cost £	Total Cost £
CT scan (1 area no contrast)	71	20	91
CT scan (1 area, post contrast only)	86	20	106
CT scan (1 area, pre and post contrast)	101	20	121
MRI (1 area no contrast)	116	22	138
MRI (1 area, post contrast only)	165	22	187
SPECT-CT (1 area)	147	26	173
SPECT scan (no CT)	133	26	158
FGD PET-CT*	797	-	-

\*Data quoted from NHS Improvement for 16/17

### Appendix 3: NICE guidelines for imaging

### NICE guideline [NG97] Published date: June 2018

#### **1.2 Diagnosis**

#### Initial assessment in non-specialist settings

- 1.2.1 At the initial assessment take a history (including cognitive, behavioral and psychological symptoms, and the impact symptoms have on their daily life):
  - from the person with suspected dementia and
  - if possible, from someone who knows the person well (such as a family member).
- 1.2.2 If dementia is still suspected after initial assessment:
  - conduct a physical examination and
  - undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline and
  - use cognitive testing.

### 1.2.3 When using cognitive testing, use a validated brief structured cognitive instrument such as:

- the 10-point cognitive screener (10-CS)
- the 6-item cognitive impairment test (6CIT)
- the 6-item screener
- the Memory Impairment Screen (MIS)
- the Mini-Cog
- Test Your Memory (TYM).
- 1.2.4 Do not rule out dementia solely because the person has a normal score on a cognitive instrument.
- 1.2.5 When taking a history from someone who knows the person with suspected dementia, consider supplementing this with a structured instrument such as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) or the Functional Activities Questionnaire (FAQ).
- 1.2.6 Refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if:
  - reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated and
  - dementia is still suspected.
- 1.2.7 If the person has suspected rapidly-progressive dementia, refer them to a neurological service with access to tests (including cerebrospinal fluid examination) for Creutzfeldt–Jakob disease and similar conditions.
- 1.2.8 For more guidance on assessing for dementia in people with learning disabilities, see the NICE guideline on mental health problems in people with learning disabilities.

### Diagnosis in specialist dementia diagnostic services

- 1.2.9 Diagnose a dementia subtype (if possible) if initial specialist assessment (including an appropriate neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out.
- 1.2.10 If Alzheimer's disease is suspected, include a test of verbal episodic memory in the assessment.
- 1.2.11 Consider neuropsychological testing if it is unclear:
  - whether the person has cognitive impairment or
  - whether their cognitive impairment is caused by dementia or
  - what the correct subtype diagnosis is.

### 1.2.12 Use validated criteria to guide clinical judgement when diagnosing dementia subtypes, such as:

- International consensus criteria for dementia with Lewy bodies
- International FTD criteria for frontotemporal dementia (progressive non-fluent aphasia and semantic dementia)
- International Frontotemporal Dementia Consortium criteria for behavioural variant frontotemporal dementia
- NINDS-AIREN criteria (National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherché et l'Enseignement en Neurosciences) for vascular dementia
- NIA criteria (National Institute on Aging) for Alzheimer's disease
- Movement disorders Society criteria for Parkinson's disease dementia
- International criteria for Creutzfeldt-Jakob disease.
- 1.2.13 Offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear.
- 1.2.14 Only consider further tests (recommendations 1.2.15–28) if:
  - it would help to diagnose a dementia subtype **and**
  - knowing more about the dementia subtype would change management.

### Further tests for Alzheimer's disease

- 1.2.15 If the diagnosis is uncertain (see recommendation 1.2.14) and Alzheimer's disease is suspected, consider either:
  - FDG-PET (fluorodeoxyglucose-positron emission tomography-CT), or perfusion SPECT (single photon emission CT) if FDG-PET is unavailable

#### or

- examining cerebrospinal fluid for:
- either total tau or total tau and phosphorylated-tau 181 and
- either amyloid beta 1–42 or amyloid beta 1–42 and amyloid beta 1–40.

If a diagnosis cannot be made after one of these tests, consider using the other one.

- 1.2.16 Be aware that the older a person is, the more likely they are to get a false positive with cerebrospinal fluid examination.
- 1.2.17 Do not rule out Alzheimer's disease based solely on the results of CT or MRI scans.
- 1.2.18 Do not use Apolipoprotein E genotyping or electroencephalography to diagnose Alzheimer's disease.
- 1.2.19 Be aware that young-onset Alzheimer's disease has a genetic cause in some people.

### Further tests for dementia with Lewy bodies

- 1.2.20 If the diagnosis is uncertain (see recommendation 1.2.14) and dementia with Lewy bodies is suspected, use 123I FP CIT SPECT.
- 1.2.21 If 123I FP CIT SPECT is unavailable, consider 123I MIBG cardiac scintigraphy.
- 1.2.22 Do not rule out dementia with Lewy bodies based solely on normal results on 123I FP CIT SPECT or 123I MIBG cardiac scintigraphy.

### Further tests for frontotemporal dementia

- 1.2.23 If the diagnosis is uncertain (see recommendation 1.2.14) and frontotemporal dementia is suspected, use either:
  - FDG-PET or
  - perfusion SPECT.
- 1.2.24 Do not rule out frontotemporal dementia based solely on the results of structural, perfusion or metabolic imaging tests.
- 1.2.25 Be aware that frontotemporal dementia has a genetic cause in some people.

Further tests for vascular dementia

- 1.2.26 If the dementia subtype is uncertain and vascular dementia is suspected, use MRI. If MRI is unavailable or contraindicated, use CT.
- 1.2.27 Do not diagnose vascular dementia based solely on vascular lesion burden.
- 1.2.28 Be aware that young-onset vascular dementia has a genetic cause in some people.

## Appendix 4: Glossary of terms and abbreviations

Term	Explanation
СТ	Computerized axial tomography
MRI	Magnetic resonance imaging
Nuclear Medicine	Nuclear medicine procedure
PET	Positron emission tomography
SPECT	Single photon emission computerised tomography
National Imaging dataset	Compiled by NHS Digital
QOF	Quality and Outcomes framework
ONS	Office for National Statistics
IoW	Isle of Wight NHS Trust
UHS	University Hospital Southampton NHS Foundation
RBCH	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
PHT	Portsmouth Hospitals NHS Trust
POOLE	Poole Hospital NHS Foundation Trust
HHFT	Hampshire Hospitals NHS Foundation Trust
DCHFT	Dorset County Hospital NHS Foundation Trust
STP	Sustainability and Transformation Partnerships
ICS	Integrated Care System

# Wessex Clinical Network: Dementia publications and products

### Supplementary information

Clinical Networks support the delivery of sustainable improvement working across all parts of the local healthcare system, following and improving patient pathways. This work is undertaken through partnership and collaborative working with multiple clinicians, providers and commissioners across both boundaries and organisations. For further information see our website *https://wessexsenate.nhs.uk/* 

# The Wessex Clinical Network has created a range of publications to support quality improvement in dementia care

**The View** – A monthly newsletter with topics highlighting useful developments in dementia and mental health in the Wessex area *https://wessexsenate.nhs.uk/clinical-networks/mhdn/* 

**Dementia research in Wessex** – The Dementia Strategy group heard from some of the studies improving care for those with dementia in Wessex and considered how to support to the relationship between research and implementation. Published January 2020

https://wessexsenate.nhs.uk/download/wessex-dementia-research/

**Younger Onset Dementia in Wessex** – Dementia presentation in younger adults has specific challenges for health and social care. The Dementia Strategy group considered how the development of a YOD Network would enable quality service development for a small population over a wide geographical area. Published January 2020

https://wessexsenate.nhs.uk/download/younger-onset-dementia-services/

A review of diagnostic imaging for dementia in Wessex – Imaging is an important part of the dementia diagnosis pathway. This review aims to understand the factors that influence this and offers recommendations for further development. Published January 2020 https://wessexsenate.nhs.uk/download/a-review-of-diagnostic-imaging-for-dementia/

**Modelling the dementia pathway** – Working collaboratively with Dorset CCG and Wessex CLAHRC we used data modelling approaches and real, local, patient-level data to understand pathway flow to diagnosis. Using this baseline, change scenarios were modelled to demonstrate short- and long-term impact on the pathway. Published July 2019

https://wessexsenate.nhs.uk/download/modelling-the-dementia-pathway/

**Antipsychotic prescribing in dementia** – Summary of guidelines, local practice and national data. Includes recommendations for local safer management. Published January 2020 *https://wessexsenate.nhs.uk/download/antipsychotic-prescribing-for-dementia/* 

**Transforming Dementia Services: Peer review and learning** – Peer review and learning - dementia care remains a key priority for the Wessex region. Two major local reviews of the Dementia pathway were undertaken in with the potential to improve care for a significant number of the local population. The Dementia Strategy Group heard presentations on both projects and considered the challenges and learning which could be shared across wider transformational projects. Published: June 2019 *https://wessexsenate.nhs.uk/download/transforming-dementia-services-peer-review-and-learning/* 

**Dementia care in Wessex is Excellent: Discovery** – Infographic defining excellence in dementia care and how the elements of a whole system approach can support this. Published January 2019 *https://wessexsenate.nhs.uk/download/a-whole-system-approach-discovery-infographic/* 

**Dementia Diagnosis Toolkit** – This toolkit was designed to support the dementia assessment process and appropriate timely diagnosis primarily for GPs diagnosing in care homes. It can also be used to rule out other conditions, provide an explanation to a person for their symptoms and allow them access to treatment and good post diagnostic support and care. Published August 2018

https://wessexsenate.nhs.uk/download/dementia-diagnosis-toolkit/

**Wessex Health Lines** – An online platform created in 2015 to share quality improvement projects in dementia which has been further developed to include Mental Health, Healthy Ageing and services for people with a neurological condition. Also included dedicated pages for neurological and cancer research. *https://wessexhealthlines.nhs.uk/* 

A strategic Vision for Mental Health, Dementia and Neurology across Wessex 2016-2020/21 – This strategic vision was the blueprint for developing mental health, dementia and neurological services across Wessex. It was written primarily with those who commission and provide these services in mind, however was also of wider interest to anyone living and working in Wessex. Published: June 2016 *https://wessexsenate.nhs.uk/download/a-strategic-vision-for-mental-health-dementia-and-neurology-across-wessex-2016-2020-21/* 

### National links

The Community Mental Health Framework for Adults and Older Adults, (September 2019), National Collaborating Centre for Mental Health – Describes a new model for place-based community mental health model moving away from siloed hard to reach services towards joined up care and whole population approaches. https://www.england.nhs.uk/wp-content/uploads/2019/09/community-mentalhealth-framework-for-adults-and-older-adults.pdf

NHS Mental Health Implementation Plan (July 2019) – Framework for delivery of the Long-Term Plan for Mental Health services. *https://www.longtermplan.nhs.uk/publication/nhs-mental-health-implementation-plan-2019-20-2023-24/* 

**NHS Long Term Plan (January 2019)** – Vision for the delivery of National Health Services over the next 10 years. *https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/* 

**Dementia Care Pathway Implementation guide and resource pack (July 18)** – Supports improvements in the delivery and quality of care and support for people living with dementia and their families and carers. *https://www.england.nhs.uk/mental-health/dementia/implementation-guide-and-resource-pack-for-dementia-care/* 

A review of diagnostic imaging for dementia in Wessex

## Notes


©Copyright reserved. Wessex Clinical Networks, January 2020. CS5620 Designed by NHS Creative