

Improving coding of dementia in primary care

Dr Paul Russell
NHS London, 2012-13

Future projections

The number of people in the UK with dementia will double in the next 40 years.

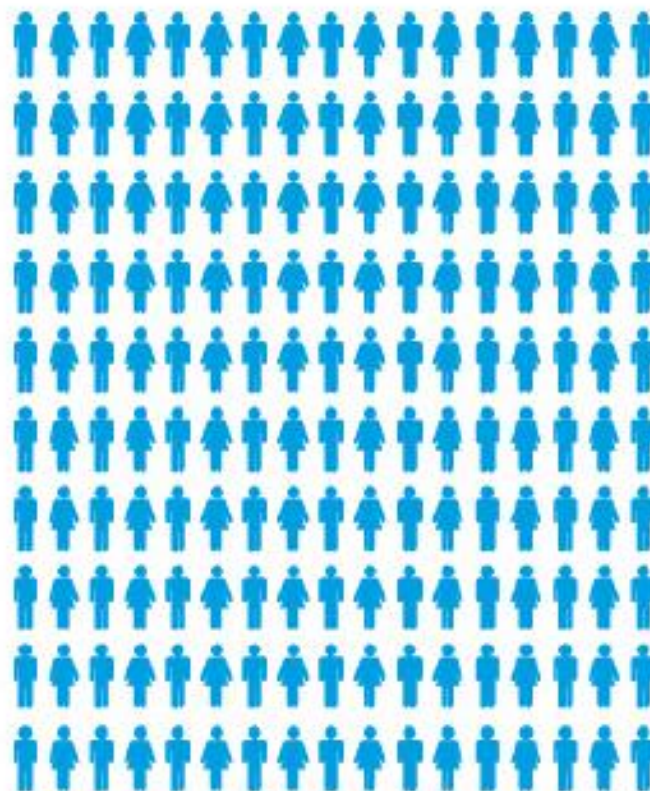
 = 10,000 people



800,000 people
with dementia in
2012



1,000,000 people
with dementia in
2021



1,700,000 people
with dementia in
2051

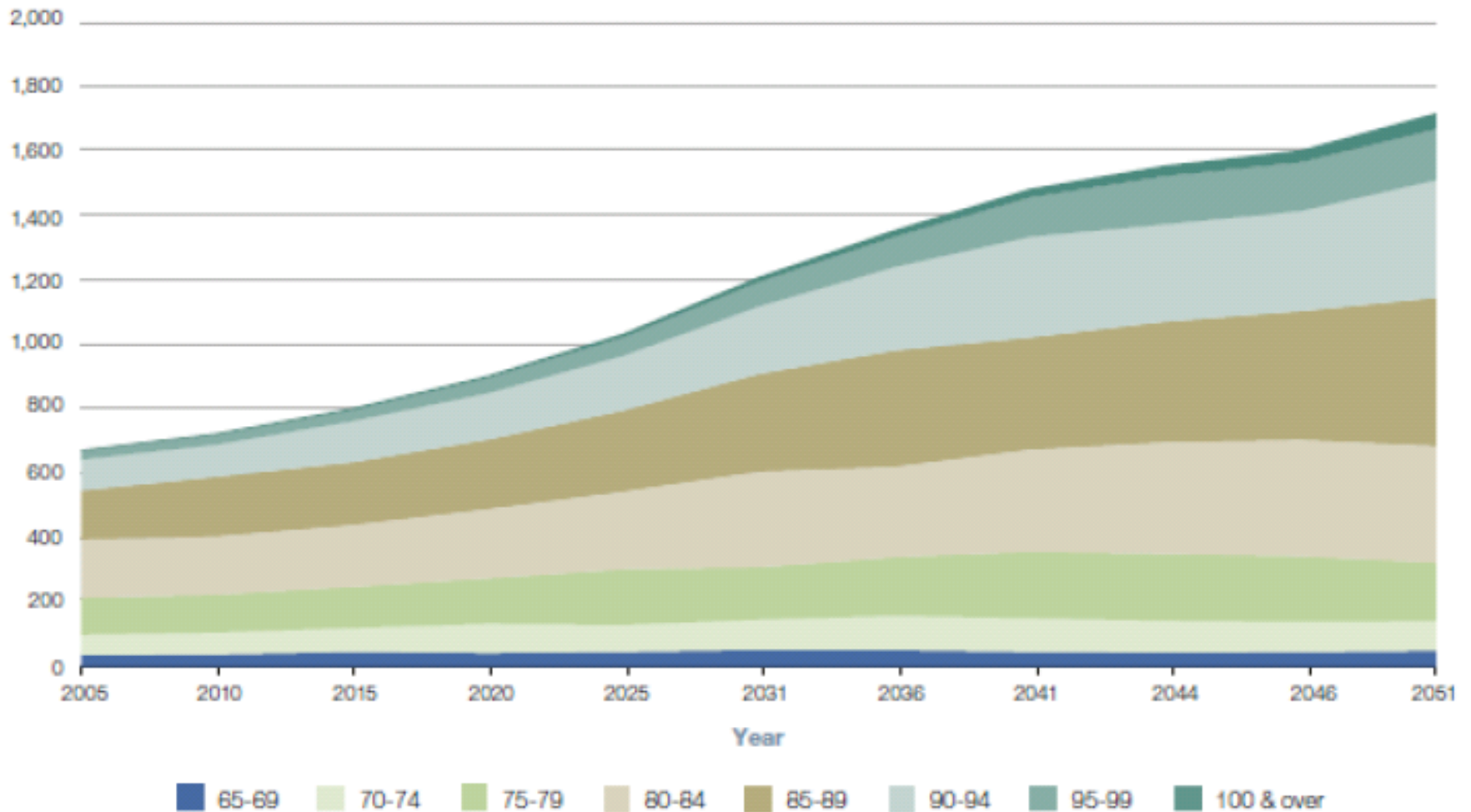
Source: Alzheimer's Society, 2012
alzheimers.org.uk

Leading the fight
against dementia
**Alzheimer's
Society**

Figure 3

Projected increase in the number of people with late-onset dementia in the UK by age group

Number of people (000s)



Source: Knapp, M et al. (2007) *Dementia UK: Report to the Alzheimer's Society, Kings College London and London School of Economics and Political Science*

(Dementia UK, 2007)

Cost to society

Some of the cost of dementia is hidden by the work done by family carers supporting people at home.

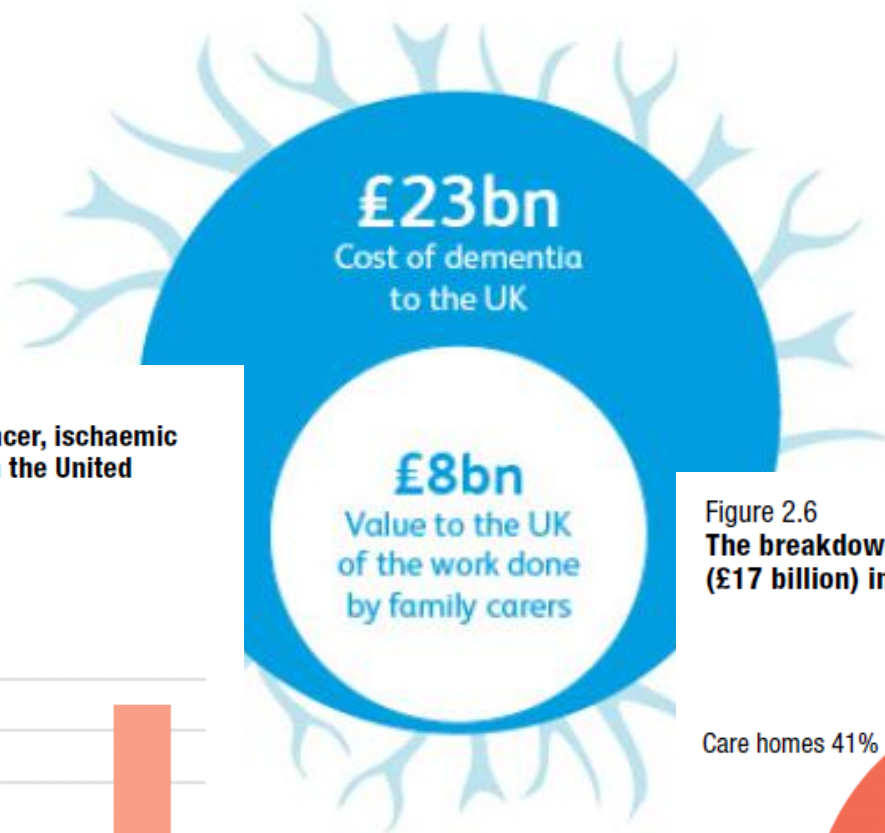


Figure 2.7
The comparative societal costs of cancer, ischaemic heart disease, stroke and dementia in the United Kingdom

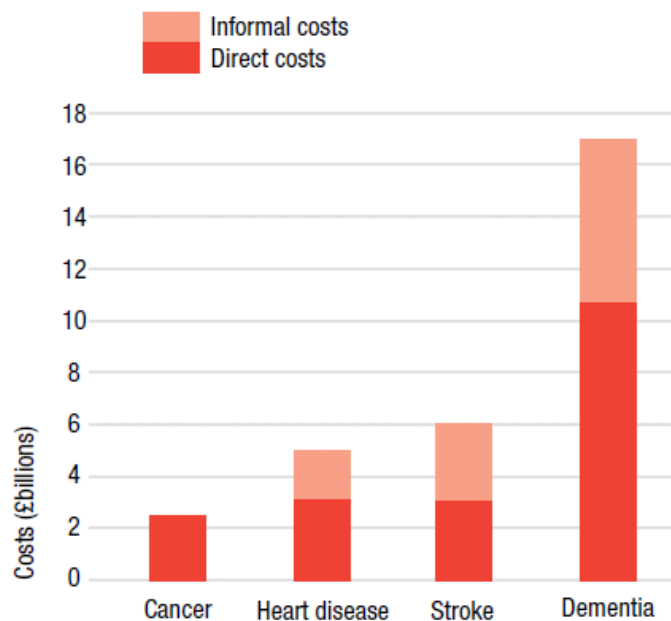
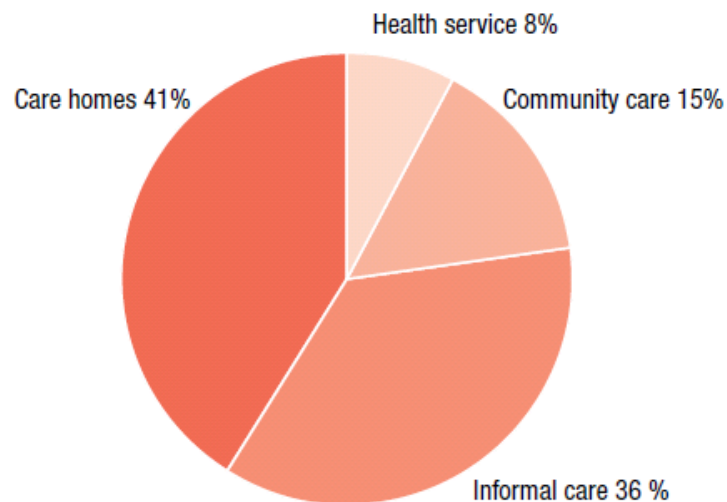


Figure 2.6
The breakdown of the total annual cost of dementia (£17 billion) in the United Kingdom ⁽⁷⁾



Case for diagnosis

- ▶ **Big drivers – increasing dementia diagnosis rates**
 - CCG's required to develop ambition for closing the diagnosis gap over the next two years

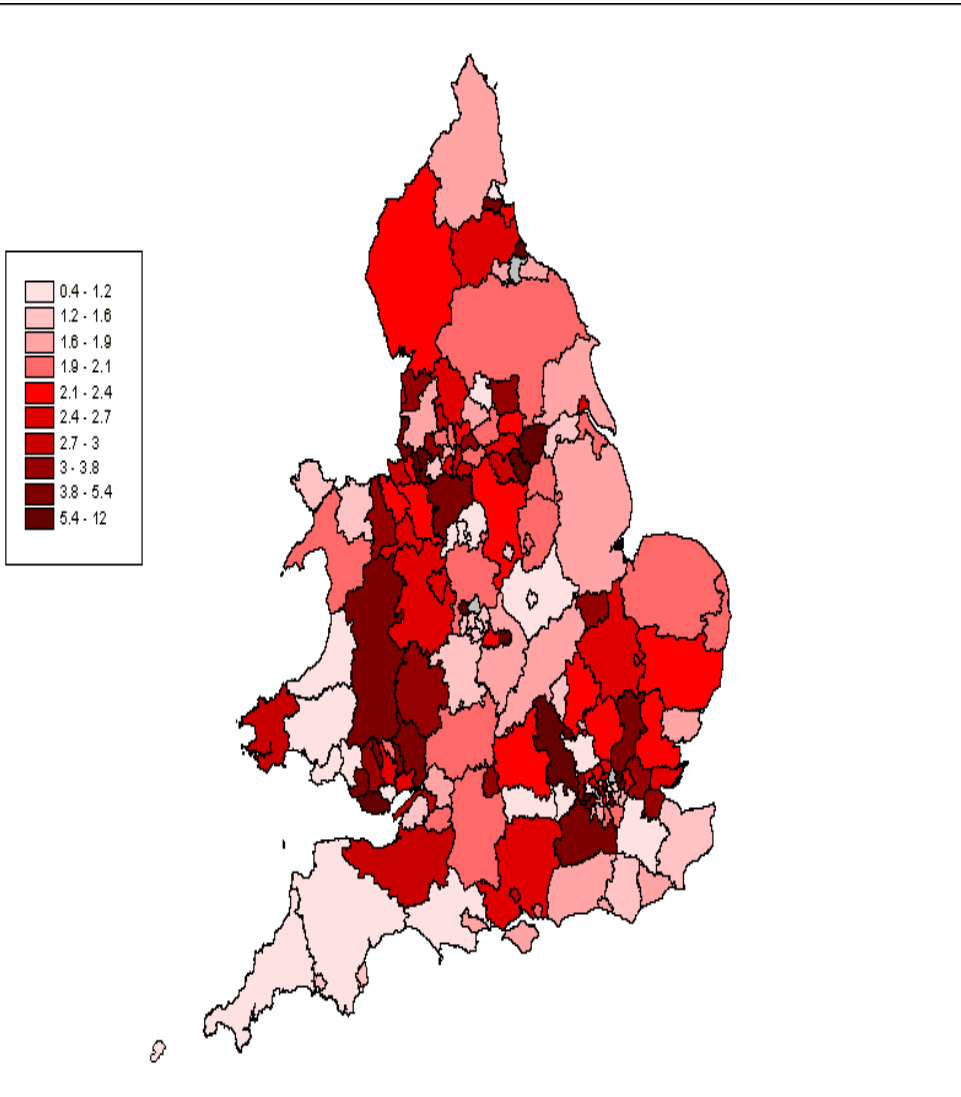
Why?

- reduce the number and length of acute hospital admissions and delay the need for long-term residential care through better planning of care

On an individual level:

- an end to uncertainty
 - enabling them to understand what is happening to them and giving them the opportunity to plan ahead, enabling them to access psychological, social, educational and pharmacological interventions which are appropriate to them
-

Where are we now in terms of dementia diagnosis?



National Dementia Prevalence (Dementia Prevalence Calculator 2013)

London Average	47.1%
National Average	46%
Islington	70.8% (Best in country)
Harrow	37.1% (Worst in London)
Castle & Rochford	32.49% (Worst in country)

Hypothesis...

- Problems in GP coding may be contributing to the reported dementia diagnosis gap

APPENDIX			
ICD10		READ	
F00	Dementia in Alzheimer's disease	E000	
F00.0	Dementia in Alzheimer's disease with early onset	E0000	
F00.1	Dementia in Alzheimer's disease with late onset	E0001	
F00.2	Dementia in Alzheimer's disease, atypical or mixed type	E0002	
F00.9	Dementia in Alzheimer's disease, unspecified	E000z	
F01	Vascular dementia Arteriosclerotic dementia	E001 E004	
F01.1	Multi-infarct dementia	E0011	
F01.2	Subcortical vascular dementia	E0012	
F01.3	Mixed cortical and subcortical vascular dementia	E0013	
F01.8	Other vascular dementia	E001y	
F01.9	Vascular dementia, unspecified Uncomplicated arteriosclerotic dementia Arteriosclerotic dementia with delirium Arteriosclerotic dementia with paranoia Arteriosclerotic dementia with depression Arteriosclerotic dementia NOS	E001z E0040 E0041 E0042 E0043 E004z	
F02	Dementia in other diseases classified elsewhere	E002	
F02.0	Dementia in Pick's disease	E0020	
F02.1	Dementia in Creutzfeldt-Jakob disease	E0021	
F02.2	Dementia in Huntington's disease	E0022	
F02.3	Dementia in Parkinson's disease	E0023	
F02.4	Dementia in HIV disease	E0024	
F02.8	Dementia in other diseases classified elsewhere	E002y	
	Dementia in conditions	E041	
F03	Unspecified dementia Presenile dementia Uncomplicated presenile dementia Presenile dementia with delirium Presenile dementia with paranoia Presenile dementia with depression Presenile dementia NOS Uncomplicated senile dementia Senile dementia with depressive or paranoid features Senile dementia with paranoia Senile dementia with depression Senile dementia with depressive or paranoid features NOS	E002z E001 E0010 E0011 E0012 E0013 E001z E000 E002 E0020 E0021 E002z	
F05.1	Delirium superimposed on dementia Senile dementia with delirium	E041 E003	
F05.9	Delirium, unspecified	E04z	
F06.0	Organic hallucinosis Other senile and presenile organic psychoses Senile or presenile psychoses	E050 E00y E00z	
F06.7	Mild cognitive disorder	E067	
F10.7	Residual and late onset psychotic disorder due to alcohol. Including: - Alcoholic dementia - Other alcoholic dementia - Chronic alcoholic brain syndrome	E07 E07 11 E01 2 E01 20	
G30	Alzheimer's disease Other Alzheimer's disease Alzheimer's disease, unspecified	F110	
G30.0	Alzheimer's disease with early onset	F1100	
G30.1	Alzheimer's disease with late onset	F1101	
G31.0	Circumscribed brain atrophy Including: - Fronto-temporal dementia - Pick's disease - Progressive isolated aphasia	No Code F111	
G31.1	Senile degeneration of the brain, not elsewhere classified	F112	
G31.8	Other specified degenerative disease of the nervous system Including: - Grey matter degeneration - Lewybody disease - Lewybody dementia - Subacute necrotizing encephalopathy	F116 E025	

"Knowledge is power with respect to diagnosis, giving those affected and their families an understanding of what is happening and the ability to make choices themselves"

National Dementia Strategy, 2009

For a copy of the London Dementia Needs Assessment or any queries about dementia diagnosis and care, please get in touch with Jen.Watt@london.nhs.uk; 020 7 932 2646

Aim:

To find out whether it is possible to raise diagnosis rates through undertaking an exercise to 'clean up' dementia coding and records at a practice level

Sample:

23 practices from across London, identified via 2012/13 London GP Dementia Development Programme

Enablers:

- ▶ Unique set of medications: (Donepezil, Galantamine, Rivastigmine, Memantine)
 - ▶ Generally similar presentation: Memory loss, cognitive decline, etc.
-



Method

- ▶ Ran searches on GP computer system of codes relevant to dementia
- ▶ Compared this list with the GP practice QOF dementia register
- ▶ Conducted a clinical review of those patients notes where there were discrepancies
- ▶ Coded dementia accurately in those found to have dementia previously diagnosed but not yet coded (back dating as appropriate)



GP Read Codes Searched

- ▶ Anti-dementia medication
 - ▶ “h/o dementia” [I46I.00]
 - ▶ “Dementia monitoring” [66h..00]
 - ▶ “Dementia annual review” [6AB..00]
 - ▶ “Cognitive decline” [28E..00]
 - ▶ “Confusion” [R009.00]
 - ▶ “Memory loss symptom” [IBIA]
 - ▶ “Memory impairment” [Z7CEH]
 - ▶ “Short term memory problems” [Z7CF8II]
-



Results

	Mean	Range	SD
Practice size	8296	2543 to 16700	3452
Initial number on register (per practice)	44	0 to 232	49
Final number on register (per practice)	50	0 to 248	54
Increase in numbers on register (per practice)	6	0 to 35	8.8



Results (2)

Variable	n	
Practice population	179,312	
Population over 65	19,562	London 861,000
Mean % over 65	10.9%	UK age 65+ 16.9% London age 65+ 11.2%

Expected dementia persons in London = **69,849**

London estimate % 65+ with dementia = **8.11%**



Results (3)

Mean % dementia of over 65s before	1007 (5.14%)	63.0% identified
Mean % dementia of over 65s after	1139 (5.82%)	71.8% identified
Absolute increase	132	(Over 23 practices)
Average number identified (per practice)	5.7	
Mean % increase in dementia diagnosis	13.1%	8.8% increase in identification rate
Mean hours spent	4.7	



Results

- ▶ 8.8% increase in absolute recognition level
- ▶ In rank terms:
 - ▶ move you up 68 places (out of 178)
 - ▶ 3-4 best in the country out of 178 in 2011-12 Alzheimer's Society change ranking (Torbay and Isle of Wight)

Somerset
South Gloucestershire
Swindon
Torbay
Wiltshire

Percentage increase in diagnosis 2011-12
4.0%
0.9%
-0.7%
8.2%
2.0%

Worsened to most improved ranking (1=most Improved, 178=most worsened) 2012
59
151
172
4
131

Area Name	Type of local health area	Number of people on QoF dementia register (number with a diagnosis) 2011	Number of people on QoF dementia register (number with a diagnosis) 2012	Estimated number of people with dementia (diagnosed and undiagnosed) 2011	Estimated number of people with dementia (diagnosed and undiagnosed) 2012	Percent of people with dementia with a diagnosis in 2011	Percent of people with dementia with a diagnosis in 2012	Percentage increase in diagnosis 2011-12	Number of people without a diagnosis 2012	Best-worst overall ranking (1=highest UK ranking, 178=lowest) 2012	Worsened to most improved ranking (1=most Improved, 178=most worsened) 2012
Somerset	PCT	3,211	3,681	8835	9132	36.3%	40.3%	4.0%	5,451	134	59
South Gloucestershire	PCT	1,116	1,187	3138	3255	35.6%	36.5%	0.9%	2,068	161	151
Swindon	PCT	967	986	2154	2232	44.9%	44.2%	-0.7%	1,246	108	172
Torbay	PCT	1,033	1,273	2662	2709	38.8%	47.0%	8.2%	1,436	78	4
Wiltshire	PCT	2,120	2,329	6502	6736	32.6%	34.6%	2.0%	4,407	169	131



Why are there problems in GP's records/coding?

- ▶ Stigma
 - ▶ Professional attitude and confidence
 - ▶ Problems over future care (?)
- ▶ Computer systems: EMIS & Vision:
 - ▶ Used by approx 98% London practices
 - ▶ Use V2-5byte read codes
 - ▶ Multitude of dementia related read codes!
 - ▶ User friendly?
- ▶ Secondary care letters
 - ▶ Lengthy psychiatric letters!
 - ▶ Diagnosis often hidden in 3rd (or 6th) paragraph
 - ▶ Often “probable dementia” at first assessment and confirmed after 3-6 months
- ▶ ICD 10 Codes



Conclusions and next steps

- ▶ **Clearly not the whole story!** – needs to be part of comprehensive whole system efforts to improve dementia care and specifically to lift diagnosis rates (through outreach, GP education, memory service commissioning, etc)
- ▶ But, exercise provides a useful first step to improve accuracy of records and management of patients, whilst also helping to close the diagnosis gap
- ▶ Can be a catalyst for broader conversations within the practice about improving care for people with dementia
- ▶ Value? (≈ 4.7 hrs GP time pp)
- ▶ Tool being revised to share nationally following pilot stage

