

This guidance document is prepared for use across the North region to provide a consistent way of coding dementia in GP practices. It was agreed by members of the north regional mental health, dementia and neurological conditions oversight group on Monday 28th July 2014 to use this guidance as the regional standard. Further changes were included in this final version following circulation to additional dementia clinical leads of north strategic clinical networks and the development of a CSU data quality tool to assist in data cleansing.

Elements of this model are adopted from NHS London Guidance on Dementia Coding produced by Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia following creation by a number of GPs working to improve dementia care in London with support from specialist experts, and Leeds North CCG to identify codes which correlate directly to the dementia register.

This guidance will be utilised in the coding clean-up exercise carried out across the North region as part of the Intervention & Support team proposal in 2014.

27th August 2014

Guidance on Dementia Coding

What is the big issue for North GPs in coding dementia?

There is a dementia diagnosis gap of 41.9% in the North, which means that only 58.1% of those who we would expect to have dementia, based on population prevalence rates, are recorded on GP practice dementia registers¹. We believe one of the reasons behind this apparently low diagnosis rate is a lack of accurate coding due to there being confusion with the available codes. This note for GPs contains guidance to help address this.

Why is it so important to diagnose and accurately code dementia?

1. It means the patient's care can be planned, managed and monitored, so that they can be signposted to supportive services and prescribed appropriate medication.
2. Diagnosis gives power to the patient and their families, as it brings clarity in terms of what is happening to them, and provides them with the ability to make choices themselves (National Dementia Strategy, 2009).
3. The coding of dementia and putting the patient on the dementia register means we can develop an accurate picture of North dementia rates to inform commissioning of high quality, cost effective services in response.
4. It means that GPs can see their own practice performance rise.

Making dementia coding simple

The North region has adopted elements of this GP dementia coding guideline from colleagues previously at NHS London (created by a team of GPs working to improve dementia care in London with support from specialist experts)² and work carried out by Leeds North CCG to identify codes which correlate directly to the dementia register.

Guideline

1. We propose the use of **eight codes** in primary care, which are listed below. Using these codes will ensure that the patient is added to the GP practice dementia register.
2. If the specific type of dementia is unknown, for whatever reason, please use the Read Code **Eu02z "Unspecified dementia"** or CTv3 code **XE1Z6**, as appropriate for your GP practice system. This can always be changed later when more information is available. Please **DO NOT** use 1461.00 "h/o dementia", 28E..00 "cognitive decline" or similar codes for this purpose – these do not allow aggregation.
3. If the patient is diagnosed with Mild Cognitive Impairment (not dementia), please use Read Code Eu057 or CTv3 code X00RS, as appropriate for your GP practice system.
4. Please use this guidance in conjunction with your local CSU developed data quality tool when conducting data cleansing.

¹ QOF data 2013/14

² Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia, Feb 2012

The main codes which General Practitioners should use to code for dementia in primary care are:

ICD code	ICD description	EMIS code	EMIS description	SystmOne code	SystmOne description
F00	Dementia in Alzheimer's disease	Eu00z	Dementia in Alzheimer's disease, unspecified	F110.	Alzheimer's disease
F00.0	Dementia in Alzheimer's disease with early onset	F1100	Alzheimer's disease with early onset	X002x	Dementia in Alzheimer's disease with early onset
F00.1	Dementia in Alzheimer's disease with late onset	F1101	Alzheimer's disease with late onset	X0030	Dementia in Alzheimer's disease with late onset
F01	Vascular dementia	Eu01z	Vascular dementia, unspecified	XE1Xs	Vascular dementia
F02.3	Dementia in Parkinson's disease	Eu023	Dementia in Parkinson's disease	Eu023	Dementia in Parkinson's disease
F03	Unspecified dementia	Eu02z	Unspecified dementia	XE1Z6	Unspecified dementia
G31.0	Circumscribed brain atrophy including: fronto-temporal dementia, Pick's disease, progressive isolated aphasia	Eu02y	Dementia in other diseases specified elsewhere	X0034	Frontotemporal dementia
G31.8	Other specified degenerative disease of the nervous system including: grey matter degeneration, lewy body disease, lewy body dementia, subacute necrotizing encephalopathy	Eu025	Lewy body dementia	XaKyY	Lewy body dementia

With thanks to NHS London and Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia and Leeds North CCG for sharing their documentation and learning to inform this guidance.

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In collaboration with the Northern England, Yorkshire & Humber, Cheshire & Merseyside and Greater Manchester, Lancashire & South Cumbria Strategic Clinical Networks.