Wessex Dementia Diagnosis Toolkit

NIHR | Applied Research Collaboration Wessex

NHS South East Clinical Delivery and Networks

The Dementia Journey

Assessment for possible dementia is not a single step but a process that takes time. It often starts with the person or family members realising that there is something wrong. Assessment proceeds through various stages and tests, and ends with sharing of the diagnosis and using this to plan the post diagnostic care. For the person and those close to them, this journey is often an uncertain, anxious and emotional one.

The Value of Good Diagnosis

This toolkit has been designed to support the assessment process and appropriate timely diagnosis. 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.

The Dementia Toolkit

This Toolkit is not a screening tool for dementia and should only be used when there is some evidence of cognitive impairment. It is not suitable to be used as an assessment of someone with a learning disability. It is intended for use as part of a clinical pathway when appropriate consent has been obtained from the patient.

This toolkit was designed and developed by the Wessex Mental Health Clinical Network and the Wessex CLAHRC to support the dementia diagnosis pathway. Any decisions made remain the responsibility of the person and where appropriate should be done in line with professional guidelines. If you have any queries please contact the Clinical Network england.wessexscn@nhs.net.

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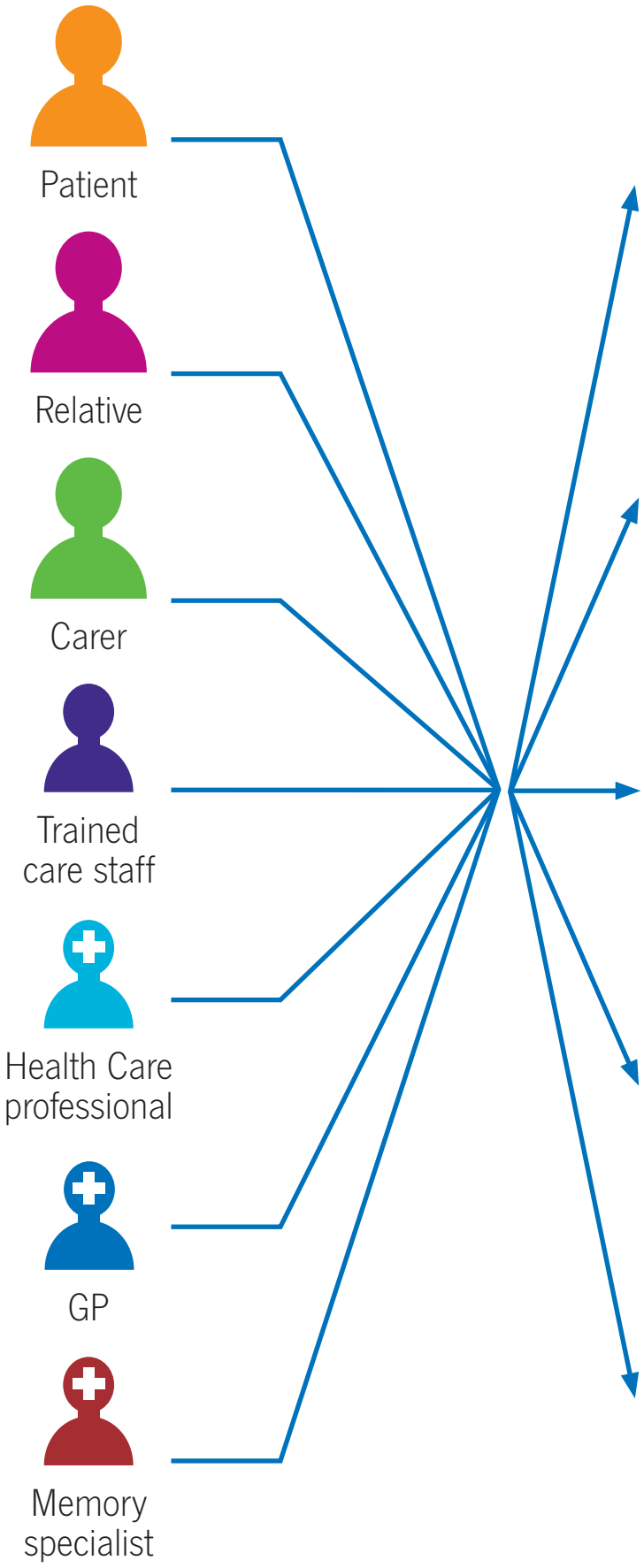
Who are you?



How can you be involved

Section A
Patient History

Led by anyone who knows the person...

Patient · Relative · Carer · Trained care staff · Health Care professional · GP

Page 5

Section B
Clinical History

Led by...

Trained care staff · Health Care professional · GP

In conjunction with...

Patient · Relative · Carer

Page 6

Section C
Assessment

Led by...

GP · Memory specialist

In conjunction with...

Patient · Relative · Carer

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Section D
Medical review and decision

Led by...

GP · Memory specialist

In conjunction with...

Patient · Relative · Carer

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Section E
Post Diagnostic Care

Led by anyone who knows the person...

Patient · Relative · Carer · Trained care staff · Health Care professional · GP

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Personal Information

Please complete the following information before starting the Toolkit assessment.

Date of assessment	
Name	
Male / Female	
Address	
Date of Birth	
Age in years	
NHS Number	
Notes	

Section Completed by:	Role:	Date:

Section A - Patient History

These items can help to identify the range of cognitive and behavioural problems which may occur in dementia

1. How is the person's memory and behaviour affected?

Do they...	Tick if present	Comments:
Have trouble remembering things that have happened recently?		
Misplace things within the home?		
Have difficulty finding the right word?		
Become restless/agitated particularly in the evenings?		

Impaired functioning is the key difference between Mild Cognitive Impairment and dementia

2. How is the persons functioning affected?

Do they...	Tick if present	Comments:
Appear to have difficulty with or show less interest in previously enjoyed activities?		
Need help/reminding with activities of daily living?		

3. How long have these problems been evident? MONTHS

These questions help define more specific characteristics of different dementias eg Alzheimer's, Vascular, Lewy Body etc.

4. What has the pattern been since it started?

Was it...	Tick if present	Comments:
Gradual deterioration		
Stepwise (decline followed by periods of stability)		
Very variable levels of confusion from day to day or week to week, observed over many months		

In cases of rapidly progressive decline with unusual symptoms, specialist assessment is recommended

Section Completed by:	Role:	Date:

Section B - Clinical History

5. Are the following conditions, relevant to dementia risk or treatment, present? (from GP records)

These items are risk factors for dementia or for increased risk if antipsychotics are prescribed.

There items are cautions in cholinesterase inhibitor drugs are used

Condition	Tick if present	Comments:
Diabetes		
Coronary heart disease		
Cerebrovascular disease		
Hypercholesterolemia		
Hypertension		
Vitamin deficiencies		
Chronic liver disease		
Epilepsy		
COPD/asthma		
Peptic ulcer disease		
Arrhythmias		

6. Blood test results. Consider ordering tests that are missing.

These items are standard QOF specified blood tests. Check whether they have been done in the previous 6 months.

Test	Done in past 6 months?	Comment on any abnormal result
Full blood count (FBC)		
Urea & electrolytes (U&E)		
Liver function test (LFT)		
Thyroid function test (TFT)		
Calcium		
Glucose		
Vitamin B12		
Folate		

It may not always be appropriate to attempt blood tests. These cases should be exception coded as part of QOF

Section B - Clinical History

7. Current medication.

Check for drugs which may be exacerbating confusion

List medications

or

attach print out of current medication from GP records

Section B - Clinical History

8. Check for clinical depression

If at least 2 out of the core 3 features are present, consider managing as depression.

Are any of the following core features of depression present	
Depressed mood for most of the past 2 weeks?	Yes / No
Lack of energy/easily fatigued	Yes / No
Loss of enjoyment	Yes / No
Details of any other depressive symptoms, including change in appetite, weight changes, sleep changes, negative thoughts, poor concentration, increasing complaints of pain etc	

9. Check lists for atypical or unusual dementias

If any 1 of these features is present together with cognitive decline specialist assessment is recommended

If any 3 of these features are present, specialist assessment is recommended

If the criterion is met, specialist assessment is recommended

Potential features of Lewy Body Disease	
Markedly variable attention & concentration for 3 months or more	Yes / No
If Yes, give duration in months:	months
Are there recurrent well-formed visual hallucinations	Yes / No
Are there Parkinsonian features (tremor/rigidity/slowness)	Yes / No
Potential features of Frontotemporal Dementia:	
Persistently disinhibited behaviour or impulsive actions	Yes / No
Persistent apathy	Yes / No
Marked loss of sympathy or interest in others	Yes / No
Repetitive movements, ritualised behaviours or stereotypical speech	Yes / No
Binge eating, or eating inedible objects	Yes / No
Potential features of Normal Pressure Hydrocephalus: Confusion together with either of the following:	
New onset walking difficulty/ataxic gait, not explained by known disease such as arthritis, stroke etc?	Yes / No
New urinary incontinence not explained by known disease?	Yes / No

Section Completed by:	Role:	Date:

Section C - Cognitive Testing

10. Cognitive testing

NHS England supports the use of the 6CIT and the MOCA for the diagnosis of dementia in primary care settings. There are other standardised reliable tests available which may be used in place of these; dependent on the assessor preference and service demand.

6CIT Score	Interpretation
0-7	Likely to be normal
8-28	Likely to be a cognitive problem

6CIT

Score	Interpretation
26-30	Likely to be normal
19-25	More likely to be MCI
0-18	More likely to be dementia

MOCA (validated for detecting MCI & early dementia)

Specific scores on cognitive tests are not in themselves diagnostic of MCI or dementia. Distinguishing between MCI and dementia is mostly dependent on the presence of associated functional impairment

Section Completed by:	Role:	Date:

Section C - Cognitive Testing

If an alternative cognitive assessment test is used in your area please affix here

Test name:

Score/outcome:

Specific scores on cognitive tests are not in themselves diagnostic of MCI or dementia. Distinguishing between MCI and dementia is mostly dependent on the presence of associated functional impairment

Section Completed by:	Role:	Date:

Section C - Cognitive Testing

Six Item Cognitive Impairment Test (6CIT)

Question	Score Range	Score
What year is it?	Correct = 0 points Incorrect = 4 points	
What month is it?	Correct = 0 point Incorrect = 3 points	
Give the patient an address phrase to remember with 5 components, e.g. John, Smith, 42, High St, Bedford		
About what time is it (within 1 hour)?	Correct = 0 points Incorrect = 3 points	
Count backwards from 20 to 1.	Correct = 0 points 1 error = 2 points More than 1 error = 4 points	
Say the months of the year in reverse	Correct = 0 points 1 error = 2 points More than 1 error = 4 points	
Repeat address phrase	Correct = 0 points 1 error = 2 points 2 errors = 4 points 3 errors = 6 points 4 errors = 8 points All incorrect = 10 points	
TOTAL 6CIT SCORE	0 – 28	/28

The 6CIT uses an inverse score and questions are weighted to produce a total out of 28. Scores of 0 -7 are considered normal and 8 or more significant

The 6 Item Cognitive Impairment Test (6CIT) Kingshill Version 2000® was developed in 1983:
Brooke P, Bullock R; Validation of a 6 item cognitive impairment test with a view to primary care usage.
Int J Geriatr Psychiatry. 1999 Nov; 14(11):936-40.

The Kingshill Research Centre, Swindon, UK owns the copyright to The Kingshill Version 2000 of the 6CIT but allows free usage to health care professionals.

Guidance and further information: www.patient.co.uk/doctor/six-item-cognitive-impairment-test-6cit

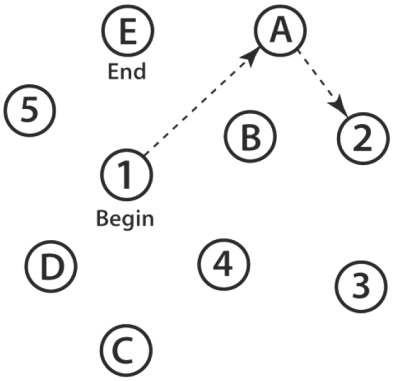
Section C - Cognitive Testing

MOCA

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE



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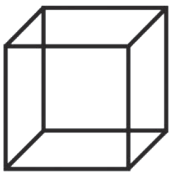


[ ] [ ]

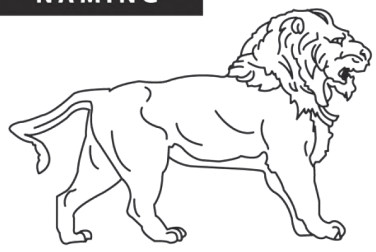
Draw CLOCK (Ten past eleven)
(3 points)

[ ] Contour [ ] Numbers [ ] Hands

POINTS

__/5

NAMING



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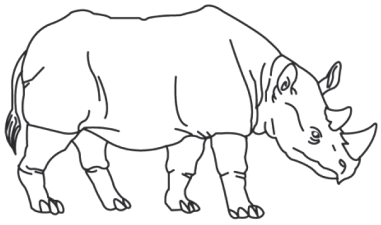

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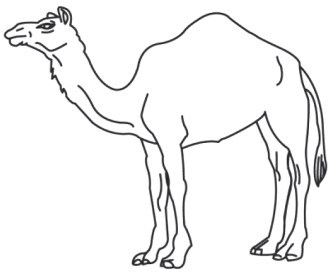

[ ]

__/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order [ ] 2 1 8 5 4

Subject has to repeat them in the backward order [ ] 7 4 2

__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

__/3

LANGUAGE Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ]

__/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words)

__/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler

__/2

DELAYED RECALL

	Has to recall words **WITH NO CUE**	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only
Optional	Category cue						
	Multiple choice cue						

__/5

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

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www.mocatest.org

Normal ≥ 26 / 30

TOTAL __/30

Add 1 point if ≤ 12 yr edu

Administered by: _____

Section D - Medical Review and Decision

11. Record your medical review and decision making in the table below

Is specialist referral required? (refer to Section A Q4 and Section B Q6)	Yes / No If yes stop here and make referral to secondary care
Is significant depression present (refer to Section B Q8)	Yes / No If yes consider first treating as per depression protocol
Is medication likely to be contributing to the confusion? (refer to Section B Q7)	Yes / No
MRI and CT Scanning NICE does not mandate a brain scan in every case of suspected dementia. However, depending on history and performance on testing, an MRI/CT scan may be requested as part of the diagnostic process. Brain scans are not recommended in the following circumstances: • Diagnosis clear • Severe dementia • Life expectancy less than one year • Recent scan is available for re-reporting	
Is brain scan required?	Yes / No
Reason for brain scan	

In principle GPs can order brain scans for the purpose of dementia diagnosis, depending on local commissioning agreements. Where this option is not yet available to GPs, it is recommended that the GP should discuss those cases potentially requiring scans with their local OPMH doctor.

12. Diagnosis - Tick option that applies, for dementia please specify type and severity. See Appendix 1 for guidance on making a diagnosis

Not dementia	Tick if applicable
Impaired cognition, but not organic (eg depression)	Tick if applicable
Dementia	Tick if applicable
Type	
Severity	
Read code	

Section Completed by:	Role:	Date:

Section E - Post Diagnostic Care

13. Next steps

Not dementia:

Offer reassurance. Reversible physical contributory factors such as medication effects should be corrected. Future reassessment can be offered either as required if the clinical presentation changes, or as a scheduled 6-12 month review.

Impaired cognition, not organic (e.g. depression):

The functional mental disorder which is thought to be causing the impairment should be managed in the usual way.

Dementia:

The diagnosis should be communicated sensitively to the patient and depending on consent and capacity, wider relatives and care providers.

Do you have consent to share the diagnosis with family?	Yes / No

14. Actions to complete

Action	Date
Assessor to provide the patient with written confirmation of their diagnosis, including the Read code, with copies to the GP and care home.	
Provide the patient and relatives with written information about dementia and maintaining well-being.	
Provide relatives with website links to access further information.	
Update the patient's personal profile e.g. "This is Me" or any other suitable personal profile.	
Look to discuss any anticipatory care needs.	
(describe any other actions taken)	
(describe any other actions taken)	

Section Completed by:	Role:	Date:

Notes

Use this page to note other relevant information

Appendix 1: Diagnostic guidance for clinicians

If the information gathered in Part C suggests the possibility of a less common dementia (Lewy Body disease, Parkinson's disease Dementia, Frontotemporal Dementia etc.), arrange specialist assessment.

Vascular risk factors (e.g. hypertension, diabetes, hypercholesterolemia etc.) are common to Alzheimer's disease and cerebrovascular disease so cannot be relied upon to distinguish between them. Most cases will be **Alzheimer's disease** or **Mixed Dementia**. **Vascular Dementia** is usually only diagnosed when there is evidence of actual stroke disease.

Note that Mild Cognitive Impairment (MCI) is a specific diagnosis which requires particular expertise and is not usually made in a primary care setting. MCI is diagnosed when the person complains of subjective memory difficulties, **and** there is objective evidence of mild impairment on testing, but there is no impairment of the person's everyday functioning.

Coding for Dementia diagnosis

The recording of diagnosis in a patient record is an important part of the diagnosis process and patient care.

The following table shows **some** of the commonly used dementia codes.

Note : Coding specifications can change and it is recommended that you check your local systems and up to date professional guidelines to ensure that coding is accurate.

Common Dementia (and related) diagnoses	ICD10 code	Commonly used Read codes	SNOMED
Dementia in Alzheimer's disease	F009	Eu00 / F110	Alzheimer's disease 26929004
Dementia in Alzheimer's disease, atypical or mixed type	F002	Eu002 / Eu01	Mixed dementia 79341000119107
Vascular dementia, unspecified	F019	Eu01 / XE1Xs	Vascular dementia 429998004
Dementia in Picks disease / frontal lobe dementia	F020	Eu020 / F111	Dementia due to Picks disease 21921000119103 Frontotemporal dementia 230270009 Dementia of the frontal lobe type 278857002
Dementia in Parkinson's disease	F023	Eu023	Dementia in Parkinson's disease 425390006
Dementia with Lewy Bodies (3)	G318	Eu025 / F116	Senile dementia of the Lewy body type 312991009 Lewy body disease/diffuse LBD 80098002
Dementia in other specified diseases classified elsewhere	F028	Eu02y	Dementia 52448006
Mental and behavioural disorders due to use of alcohol, residual and late onset psychotic disorder (Alcohol related dementias)	F107	E012 A411. / Eu021 / F11x7	Dementia associated with alcoholism 281004 Chronic alcoholic brain syndrome 191475009 Dementia due to Creutzfeldt Jakob disease 429458009
Unspecified dementia	F03X	Eu02z	Dementia 52448006
Drug induced dementia		E02y1	Drug induced dementia 191493005
Mild cognitive impairment (4)	F067	EU057 / X00RS / Xaagi	MCI 386805003
Senile and pre-senile organic psychotic conditions	-	E00	Senile dementia 15662003 Pre-senile dementia 12348006
Delirium	F050	-	Delirium 2776000

What is the Mental Health Services Data Set?

The MHSDS is a patient level, output based, secondary uses data set which delivers robust, comprehensive, nationally consistent and comparable person-based information for children, young people and adults who are in contact with Mental Health Services. As a secondary uses data set it intends to re-use clinical and operational data for purposes other than direct patient care.

Diagnosis codes are used as part of national dataset to commissioning

- clinical audit
- research
- service planning
- inspection and regulation
- monitoring government policies and legislation
- local and national performance management and benchmarking
- national reporting and analysis

What is ICD Coding?

ICD is the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. It is the diagnostic classification standard for all clinical and research purposes. ICD defines the universe of diseases, disorders, injuries and other related health conditions, listed in a comprehensive, hierarchical fashion that allows for:

- easy storage, retrieval and analysis of health information for evidenced-based decision-making;
- sharing and comparing health information between hospitals, regions, settings and countries; and
- data comparisons in the same location across different time periods.

Uses include monitoring of the incidence and prevalence of diseases, observing reimbursements and resource allocation trends, and keeping track of safety and quality guidelines. They also include the counting of deaths as well as diseases, injuries, symptoms, reasons for encounter, factors that influence health status, and external causes of disease.

ICD10 was introduced in 2016 and remains currently in use. ICD11 was released for on 18th June 18 for testing and translating in internationals systems with the expectation that it will go live on 1 January 2022.

For more information please follow the following link: http://www.who.int/classifications/icd/en/

What are Read codes and when do Read Version 2 and Clinical Terms Version 3 retire?

Read Codes are a coded thesaurus of clinical terms. They have been used in the NHS since 1985. There are two versions: version 2 (v2) and version 3 (CTV3 or v3). Both versions provide a standard vocabulary for clinicians to record patient findings and procedures, in health and social care IT systems across primary and secondary care. The last updated release of Read v2 was April 2016, and there will be no further update to CTV3 following the April 2018 release. For more information please see

https://digital.nhs.uk/services/terminology-and-classifications/read-codes

Quality and Outcomes Framework (QOF) indicators can also change along with the coding. Up to date guidance can be found at https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/quality-and-outcomes-framework-qof

What is SNOMED coding?

The transition from using Read codes in primary care to using SNOMED CT is being managed under the national GPSoC framework. SNOMED CT will go live in general practice care in a phased approach from April 2018. The following weblink gives more information.https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct/snomed-ct-implementation-in-primary-care

PLEASE NOTE: SNOMED CT is a dynamic resource with comprehensive, scientifically validated clinical content. It is in use in over fifty countries, mapped to other International standards, and updated in line with a release schedule, so there can be changes to content over releases. The SNOMED CT UK Edition is released twice per year and consists of the International Edition plus the UK-specific content provided within the UK Clinical Extension and UK Drug Extension. To investigate/confirm any codes provided in the resource, or identify additional codes, please refer to the NHS Digital SNOMED CT browser: https://termbrowser.nhs.uk/?

Survey

This Dementia Toolkit was developed by the Wessex Clinical Network and CLAHRC (Collaborations for Leadership in Applied Health Research and Care). We aim to use the best available information and data to improve the delivery of care across Wessex. Your opinion matters to us and we would like to hear your views on the Dementia Diagnosis Toolkit.

1. Please tell us who you are:

GP ☐
Care home staff ☐
Individual with a memory concern ☐
Family member ☐
Other (please detail) ☐

2. What decision was made through using the Dementia Diagnosis Toolkit?

Diagnosis of dementia made by GP ☐
Diagnosis of dementia made by Older Persons Psychiatrist ☐
Referral to memory assessment service was made ☐
A diagnosis of depression or delirium was made by GP ☐
No dementia was found to be present at this time ☐
Other (please detail) ☐

3. Did using the Toolkit result in any actions or improvements for someone you provide care to? Please describe briefly.

4. Would you use this Toolkit again?

Very likely ☐ Likely ☐ neither likely nor unlikely ☐ Unlikely ☐ Very unlikely ☐

5. How easy was the Toolkit to use?

Very easy ☐ Easy ☐ Neither easy nor difficult ☐ Difficult ☐ Very difficult ☐

6. How could we improve the Toolkit?

7. Any other comments?

If you would rather email us with your comments, please do so via email to Dementia Quality Improvement Lead email: england.wessexscn@nhs.net or complete the online survey at https://bit.ly/2KIlrBT

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