Dementia:
Challenges in Diagnosis

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Declarations of Interest

- NHS:
  - CN SE Clinical Lead Dementia
  - Co-developer of MoodHive (Depression Anxiety Pathway)
- Royal College of General Practitioners
  - Clinical Representative Dementia
  - Member Learning Disability Special Interest Group
  - Founder of Dementia Roadmap
- Consultancy / Advisory Boards / Speakers Bureau:
  - Alz Soc, Biogen, Cerestim Ltd, Chase Pharmaceuticals, ConSynance, Edmund de Rothschild, Eli Lilly, Ieso, Lundbeck, Roche, Wellcome Trust
  - psi-napse

Overview

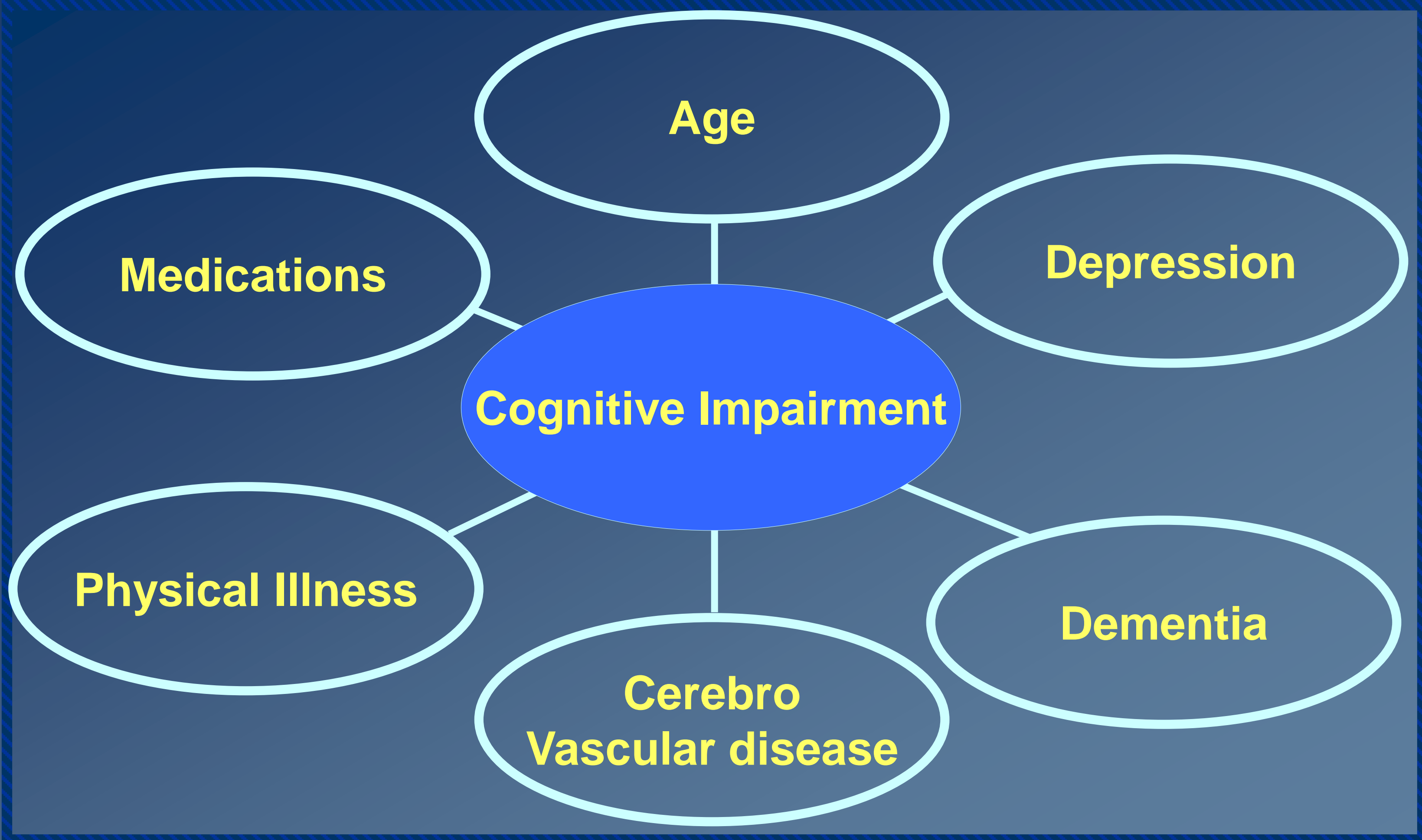
Diagnostic Challenges in Dementia

- Care Home Case finding
- Learning Disability
- Mild Cognitive Impairment
- Young Onset Dementia
- Implications for Policy and Practice

Dementia Challenges in Diagnosis: Care Homes

- Most focus has been on Memory Assessment services (MAS)
  - Many of the Missing Cases are not suitable for MAS
- Lack of appreciation why a Dementia Diagnosis matters for people in Care Homes:
  - Approach to and Quality of Care:
    - Communication, FEET (Feet, Eyes, Ears, Teeth), PAIN
  - Impact on management of co-morbidities – central computer not working
- Resources? Need collaborative working involving wider primary, health and social care team
- Technology:
  - Information sharing
  - Holistic care plan templates

Cognitive Impairment: Contributions – Not all Dementia !



Patient Review - Care Homes

Oakhurst Pt ID	DNAR	LPA Health &or Welfare	BP	Weight KG	Blood tests / Monitoring	Registers / Comments
	Y		128/77	64.1	FBC U&Es, LFTs Fasting lipid profile, thyroid function, annual Mar, BP & wt mthly	Dementia; hypothyroidism
	Y	Y (Finance)	125/75	72.1	FBC U&Es, LFTs, valproate level, Annual Feb, BP & wt, monthly	CKD, COPD, Dementia, Diabetes, Epilepsy (May 15), Hypertension
	Y		100 / 60	41.7	FBC U&Es, LFTs Fasting lipid profile, thyroid function, annual Jul, BP & wt mthly,	COPD, Hypertension, Dementia
			121/70	49.5		To be reviewed
			126 /74	88.7	FBC U&Es, LFTs fasting lipid profile glucose thyroid function, annual Nov, BP, wt mthly	Dementia, Stroke; hypothyroidism
	Y		119/76	72.0	FBC U&Es, LFTs fasting lipid profile HbA1c, annual ???, BP & wt mthly	Asthma, Dementia, Diabetes, Hypertension
	Y	Y finance	115/69	51.3	FBC U&Es, LFTs fasting lipid profile, Annual ???, BP & wt monthly	Dementia, Hypertension
	Y		121/90	53.0	FBC U&Es, Annual ???, BP & wt monthly	Dementia
	N		120/80	53		To be reviewed
	Y		118/76			To be reviewed
	Y		128/75	52.0	FBC U&Es, LFTs, HbA1C fasting lipid profile, Annual Sept, BP & wt monthly	CKD, Dementia, Diabetes (Oct review), Hypertension, registered Blind
	Y		125/75	65.4		To be reviewed

Dementia Challenges in Diagnosis: Care Homes

DeAR-GP
User Guide

Foreword | DeAR-GP process | Checklist | Evaluation and data sharing | Resources | Supporting materials

Download our Dementia Assessment Referral to GP Form

Ref: www.dear-gp.org

DiADem Tool

DiADeM Tool – Diagnosing Advanced Dementia Mandate (*for care home setting*)

A diagnosis of dementia is usually made within memory services. Some care home residents with advanced dementia have never had a formal diagnosis. In these cases a referral to memory services is rarely desirable. It is likely to be distressing for the individual and is usually unnecessary[1]. People with advanced dementia, their families and staff caring for them, still benefit from a formal diagnosis. It enables access to appropriate care to meet individual needs and prompts staff to consider MCA and DOLs issues where appropriate.
A diagnosis of dementia can be made with a high degree of certainty if ***all five*** criteria listed below are met: ✓

1. Functional impairment
The person is ***no longer fully independent*** in relation to basic activities of daily living, washing, dressing, feeding and attending to own continence needs. The requirement of prompting or supervision of staff constitutes a loss of full independence. ☐

2. Cognitive impairment – 6 CIT assessment

Question	Scoring	Score achieved
1. What year is it?	Correct – 0 points, incorrect – 4 points	
2. What month is it?	Correct – 0 points; Incorrect – 3 points	
3. Give an address phase to remember with 5 components e.g. John, Smith, 42, High St, Wakefield		
4. About what time is it (within 1 hour)	Correct – 0 points; Incorrect – 3 points	
5. Count backwards from 20-1	No errors – 0 points; 1 error – 2 points; more than 1 error – 4 points	
6. Say the months of the year in reverse	No errors – 0 points; 1 error – 2 points; more than 1 error – 4 points	
7. Repeat address phase	No errors – 0 points; score 2 points for every component wrong e.g. 3 errors, 6 points	
TOTAL SCORE:		

6 CIT scores: 7 and below normal; *8 and above indicate impairment.*
Assessment tools other than 6CIT can be used. If used does score indicate impairment Y/N? Y/N
NB. Scores obtained in this patient group would be expected to be at the severe end of scale and for some patients their cognitive impairment will be of such severity that they cannot undertake the assessment. ☐

3. Corroborating History
History of gradual cognitive decline (typically for the last few years) is confirmed by care staff, relatives and medical records. Staff/relatives confirm that in their opinion the patient ***consistently demonstrates both functional and cognitive impairment***. ☐

4. Investigations
Dementia screening ***bloods are normal*** (where clinically appropriate and patient consents to bloods). If patient lacks capacity to consent to bloods, a best interest decision must be made and documented accordingly.
NB. If intracranial pathology (e.g. subdural haematoma, cerebral tumour) is suspected, referral for a brain scan may be appropriate. Otherwise where dementia is advanced, differential diagnosis is unlikely to affect patient management & a brain scan is unnecessary. ☐

5. Exclusion Criteria
There is ***no acute underlying cause to explain confusion*** i.e. delirium (acute confusional state) has been excluded. Mood disorder or psychosis is also excluded. ☐

Ref: http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Care%20Settings/Care%20homes/DiADeM%20v3.pdf

Dementia in People with Learning Disability

- Overall 7 times more likely to develop dementia
- People with Down's Syndrome at highest risk; Incidence
  - 1 in 50 aged 30-39 yrs
  - 1 in 10 aged 40-49 yrs
  - 1 in 3 aged 50-59 yrs
  - Over 50% aged ≥ 60 yrs
- Less likely to receive a correct or early diagnosis OR be able to understand the significance of the diagnosis
- Will require specific support to:
  - Understand the changes they are experiencing
  - Access appropriate services after diagnosis & as dementia progresses

Require Commissioning of appropriate services

Dementia in People with Learning Disability: Comparative Prevalence

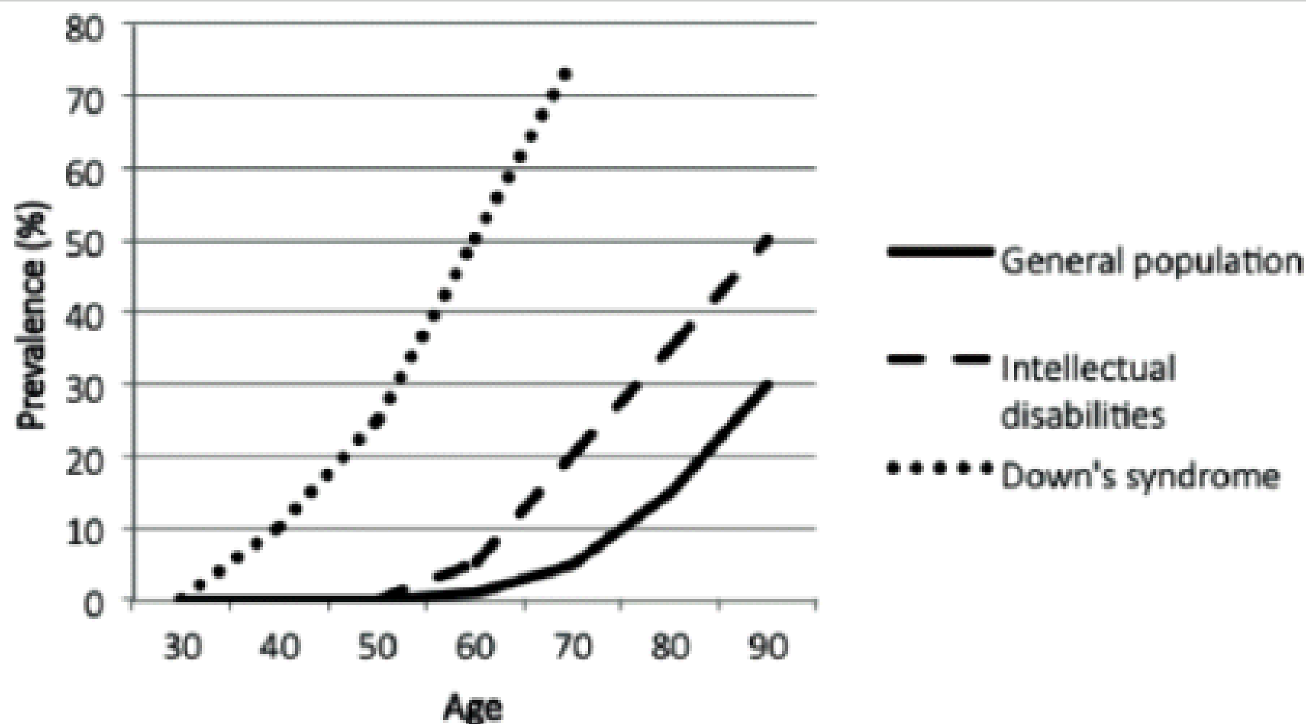
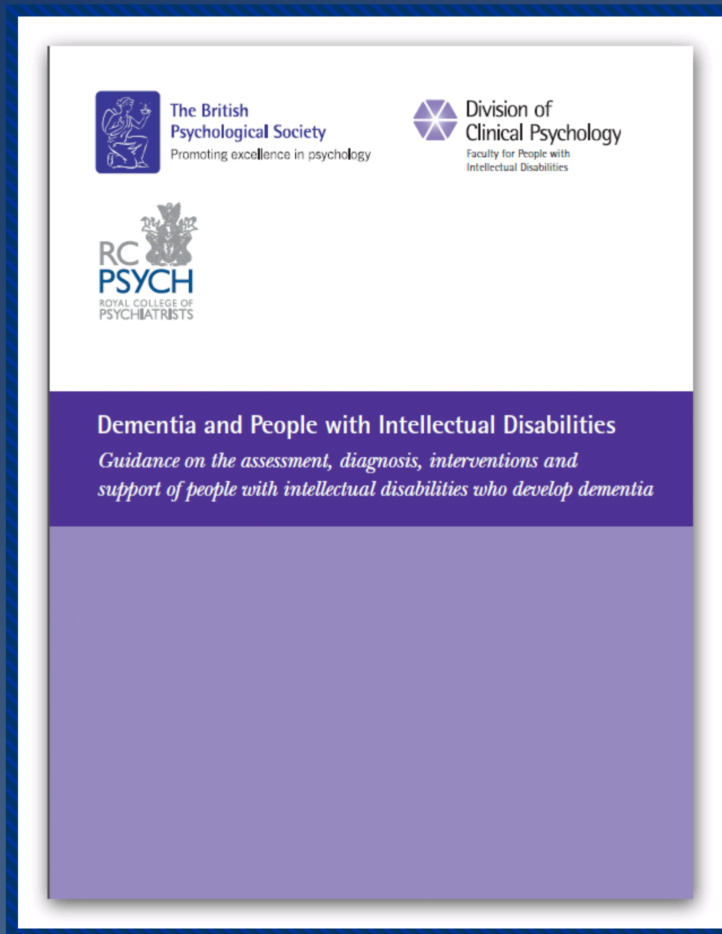


Figure 1: Comparison of dementia prevalence rates by age

Ref: Strydom 2014

Dementia in People with Learning Disability



Most cases need specialist assessment

- Screening:
  - Dementia Questionnaire for People with Learning Disabilities
  - Dementia Scale for Down's Syndrome (DSDS)
- Neuropsychological Assessments
  - Neuropsychological Assessment of Dementia in Adults with Intellectual Disabilities (NAID).
- The Glasgow Depression Scale (GDS-LD)
- Some milder cases of LD with suspected dementia may be referred to MAS

Ref: Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia

Dementia Challenges in Diagnosis: Mild Cognitive Impairment

- Affects 20% ≥65; 15 times more likely to develop dementia
- People given a diagnosis of MCI are worried that they have / are developing, Alzheimer's disease or another subtype of dementia
  - Up to 1/3 of people seen in MAS diagnosed with MCI
- MCI is different from normal ageing
  - People have difficulty with memory, executive function
- MCI differs from dementia:
  - Dementia affects a person’s everyday activities and is more than just memory / executive function loss
- Lack of national clinical guidance about recognition and management
  - Research criteria
- Advice:
  - importance of healthy lifestyle (exercise, alcohol, no smoking), nutrition, keeping your brain active (puzzles, cross words, suduko).

Dementia Challenges in Diagnosis: Mild Cognitive Impairment

Recommendations

- All patients with MCI should be coded on Primary Care Systems using the following codes: Read Code Eu057 or CTv3 code X00RS
- Include MCI on the "Problem Page" or equivalent of the pt record so apparent whenever the pt attends an appointment
- Pts with MCI should be reviewed in Primary Care at least Annually
  - Combine with other reviews
  - Opportunistic
- Ask two simple questions about memory and / or functioning.
- Examples of two questions:
  - Do you remember being referred to a specialist clinic last year to investigate how well you remember things? How are things now – better, the same or are you concerned?
  - How are you coping with every day things e.g. bills, remembering family events, driving

Brief Dementia Screening Indicator for Primary Care

Do you think your patient may have cognitive impairment based on:

□ your observations □ concerns of patient □ concerns of family or others

If yes to any: Your patient should be screened for cognitive impairment.

Is your patient age 80 years or older? □ yes □ no

If yes: Your patient should be screened for cognitive impairment.

If no: Administer Dementia Screening Indicator.

Dementia Screening Indicator			Points
1. How old is your patient? __________ years *If 65-79 years, assign 1 point per year above age 65. Example: age 65 years receives 0 points; age 72 years receives 7 points.*			
2. Does your patient have < 12 years of education?[1]	No (0)	Yes (9)	
3. Is your patient's BMI < 18.5 kg/m^2?[2]	No (0)	Yes (8)	
4. Does your patient have a history of type 2 diabetes?	No (0)	Yes (3)	
5. Has your patient ever had a stroke?	No (0)	Yes (6)	
6. Does your patient need help from others to manage money or medications?[3]	No (0)	Yes (10)	
7. Does your patient currently take anti-depressant medications OR report that "everything was an effort" ≥3 days per week over the past week?[4]	No (0)	Yes (6)	
Total point score: *If ≥ 22, your patient should be screened for cognitive impairment.*			

Ref: Barnes Alzheimer's & Dementia 10 (2014) 656–665

Dementia Challenges in Diagnosis: Young Onset Dementia

- Case-mix more complex and diverse:
  - Worried well; Functional cognitive disorder
  - Psychiatric / MH problem presenting with memory symptoms
  - Alcohol and drug misuse
  - Rarer organic causes of cognitive impairment
  - Overlap with “neurological” disorders
- Distinguishing above from neurodegenerative disorder is complex
  - Need appropriate expertise
  - Insufficient expertise leads to diagnostic error
- Atypical forms of Alz dis and Frontotemporal dementia common
  - Vascular / mixed rare
- Implications of diagnosis and misdiagnosis extremely significant

Dementia Challenges in Diagnosis: Young Onset Dementia

Issues:

- Delays in diagnosis common
- Impact on family (financial, personal, social)
  - Often working age with financial responsibilities
- Current Memory Assessment Service specification doesn't ensure that services are competent to assess atypical cases
  - Integration of neurology and MAS services
  - Link neurology with community MH services
  - YoD lead for each STP ?
- Often discharged from services after diagnosis
- Lack of age-appropriate support services – community, hospital, residential

Dementia Challenges in Diagnosis

All potential pt groups – not just MAS referrals

Not just for Primary Care it is everyone's responsibility

- Community Pharmacist
- Community Team (Matrons, District Nurses)
- Multidisciplinary Team – incontinence, falls
- Practice Nurses – LT condition reviews
- Social Care
- Specialist nurses - Diabetic, Parkinson's

People in the Community

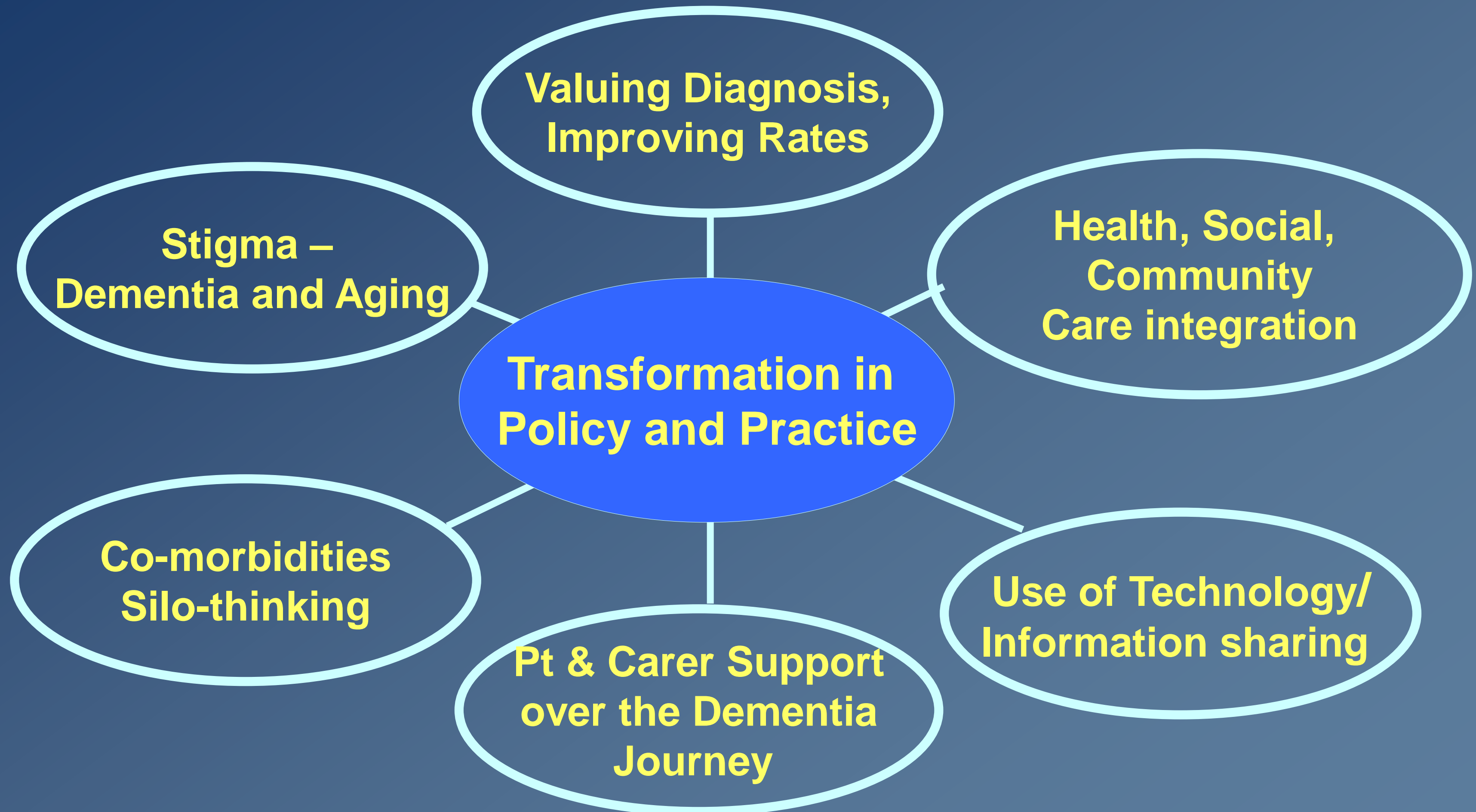
- Information often hidden in letters from Acute Trusts, MH and Memory Assessment Services

People in Care Homes:

- Information often "hidden" in pt notes
- Care-workers

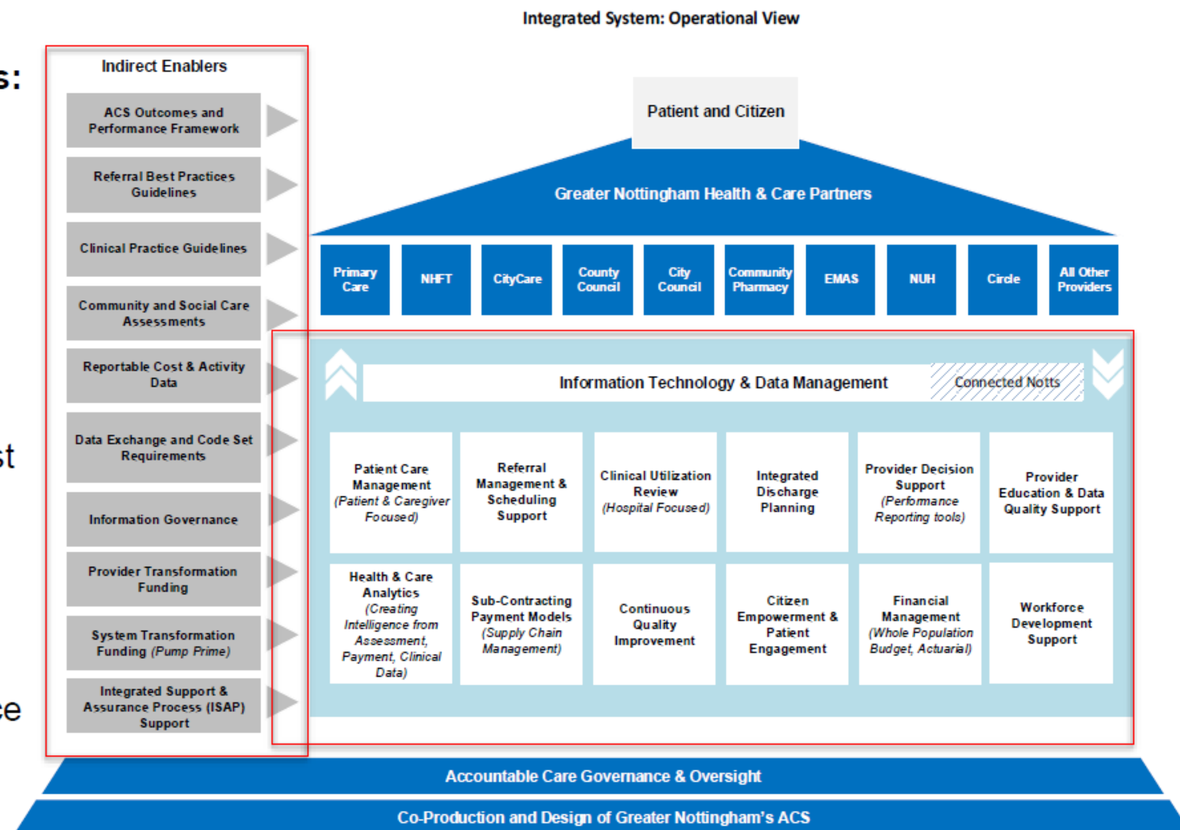
Dementia Recognition needs to be embedded in everyday practice to maintain Dementia Registers and Provide Quality Care across the Dementia Journey

Dementia: Issues and Challenges



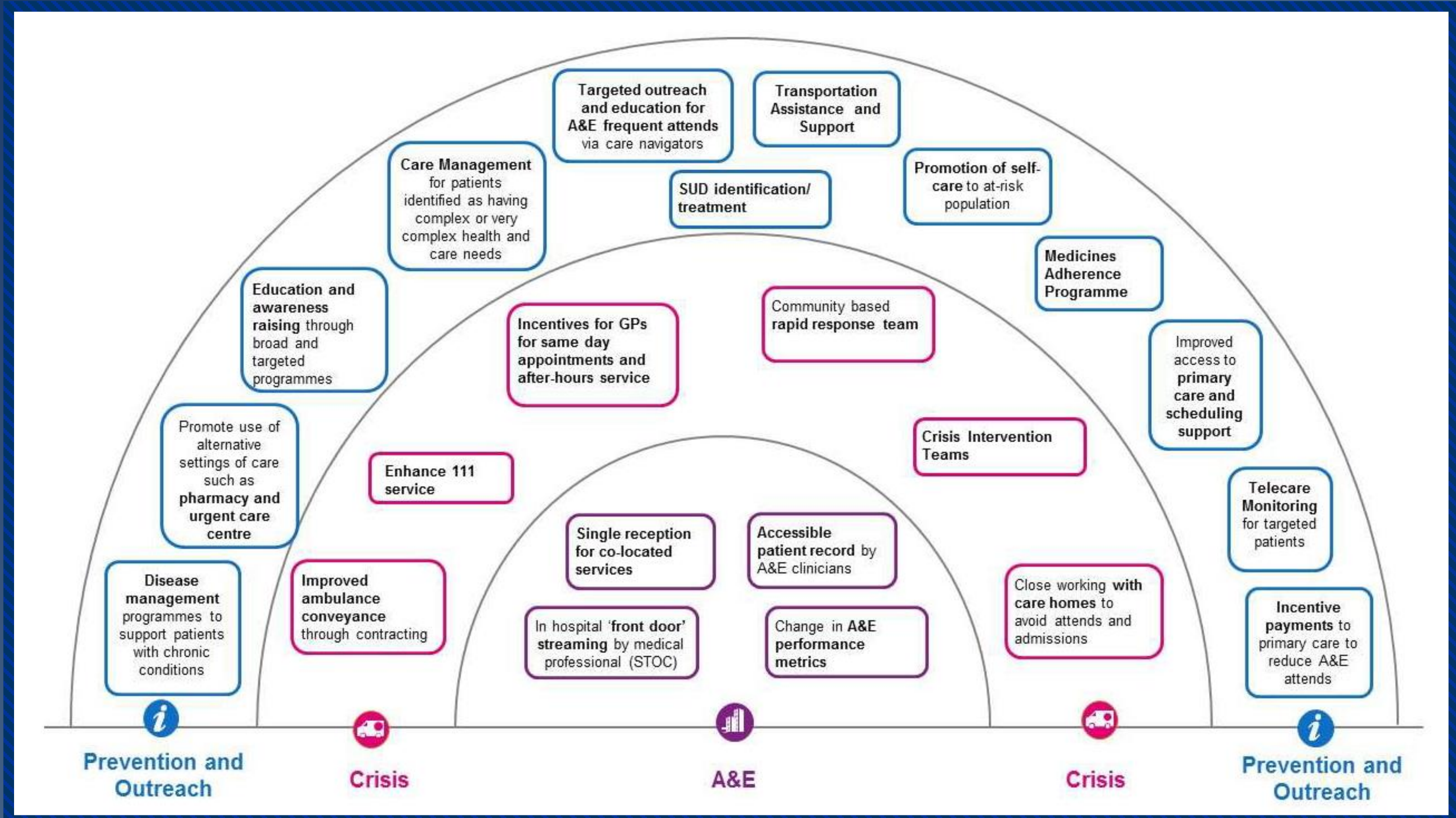
Transformation: What this looks like in Practice
A New System of Care

- **Indirect Enablers:** One-off investments and regulatory/legal actions
- **Integration Functions:** Functions and activities that must be performed continuously
- All the Enablers and Functions need to be in place to achieve sustainable improvement and financially viable system



Ref: Greater Nottingham Transformation Partnership Nov 2017

Transformation: What this looks like in Practice
Population Health Care Model



Ref: Greater Nottingham Transformation Partnership Nov 2017

Thank You

Dementia Recognition & Management

- We are doing better BUT there is still room for further improvement
- Recognition of people “at risk of” and “with dementia” is an ongoing process that needs to be embedded in every day practice throughout health and social care if:
  - Dementia Diagnosis Rates are to be achieved and maintained
  - Resources in health, social care and communities are to be used efficiently and effectively
  - Quality and Life of people with dementia their family and carers throughout the Dementia Journey is to be optimised
- Increasing role for Primary Care in Management

Dementia the NEW DIABETES –

We need similar resources!

Dementia Case-Finding

- Data searches (Harmonisation) regularly:
  - Dementia register
  - Delirium
  - Medications
- Case note searches – especially new pts "at risk"
  - New pts:
    - Community
    - Care Homes
- Memory Assessment Referrals
  - Review outcome
- Pts at risk:
  - Opportunistic questions at QoF review

Dementia Case-Finding

- Medications used to treat dementia – Alz Dis, PDD
  - Acetyl Cholinesterase inhibitors
    - Donezepil (Aricept® , Aricept Evess®); Galantamine (Reminyl®, Reminyl® XL); Rivastigmine (Exelon®);
  - Memantine hydrochloride (Ebixa®)
- Not just CURRENT use; EVER used
- Behavioural and psychological symptoms of Dementia (BPSD)
  - Cholinesterase inhibitors, Antipsychotics, BZDs
- Outcome of referrals
  - Memory Clinic - ? Diagnosis hidden in the text
  - Also remember referrals to:
    - Neurologist – younger / atypical
    - Geriatrician – co-morbidities
    - Learning Disability services
- Residents in Nursing / Care Home – especially new pts
  - NICE Apr 2013: Asking GPs to have a system to regularly review people living in residential homes to consider if a diagnosis of dementia is indicated

Dementia Case-finding

Description¤	Read·Code¤	CTv3·code¤
H/O·Dementia¤	1461.¤	1461.¤
Dementia·Monitoring¤	66h..¤	XaMJC¤
Dementia·Annual·Review¤	6AB..¤	XaMGF¤
Cognitive·Decline¤	28E..¤	*No·equivalent*¤
Impaired·Cognition¤	28E3.¤	Ua189¤
Severe·Cognitive·Impairment¤	28E2.¤	Xaagk¤
Moderate·Cognitive·Impairment¤	28E1.¤	Xaagj¤
Confusion¤	R009.¤	R009.¤
Confused¤	2841.¤	2841.¤
Intermittent·confusion¤	-¤	Xa1sZ¤
Poor·short·term·memory·¤	-¤	X75xH¤
Poor·long·term·memory¤	-¤	X75xC¤
Memory·Impairment¤	-¤	X75xU¤
Short·term·memory·problems¤	1B1A1¤	*No·equivalent*¤
Forgetful¤	28G..¤	X75xV¤
Memory·lapses¤	-¤	Ua197¤
Age-associated·memory·impairment¤	-¤	X00RT¤
Onset·of·confusion¤	-¤	Ua1W9¤

- Codes suggestive of dementia
  - Memory Impairment, Mild Cognitive Impairment
- Old EMIS Codes:
  - EMIS LV to EMIS web
- Medications used to treat dementias
- Specific populations:
  - Learning Disability
  - Delirium
- Mild Cognitive Impairment
  - Read Code Eu057;
  - CTv3 code X00RS

Dementia Coding

Diagnostic description	Read Code (e.g. EMIS systems)	CTv3 code (e.g. SystmOne)
Alzheimer's Disease	Eu00z	F110.
Alzheimer's Disease with early onset	F1100	X002x
Alzheimer's Disease with late onset	F1101	X0030
Vascular dementia	Eu01z	XE1XS
Dementia in Parkinson's disease	Eu023	Eu023
Fronto-temporal dementia	Eu02y	X0034
Lewy body dementia	Eu025	XaKyY
Mixed dementia	Eu002	Eu002
Unspecified dementia	Eu02z	XE1Z6