



Setting standards for dementia

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Areas to cover

- Using evidence to set standards for prevention, treatment and care
- Measuring and monitoring quality
- Looking to the future – what's on the horizon?



Core principles of NICE guidance

- Comprehensive evidence base – not just RCTS
- Expert input - from clinicians, economists etc
- Patient and public involvement
- **Independent advisory committees**
- Genuine consultation with all stakeholders
- Regular review and updating
- Open and transparent process – meetings held in public.



Guidance and advice on dementia

Guidance

- Dementia – clinical guideline (update under consideration)
- Disability, dementia and frailty – mid-life approaches to prevention
- Donepezil, galantamine, rivastigmine and memantine for Alzheimer's disease – TA

Advice

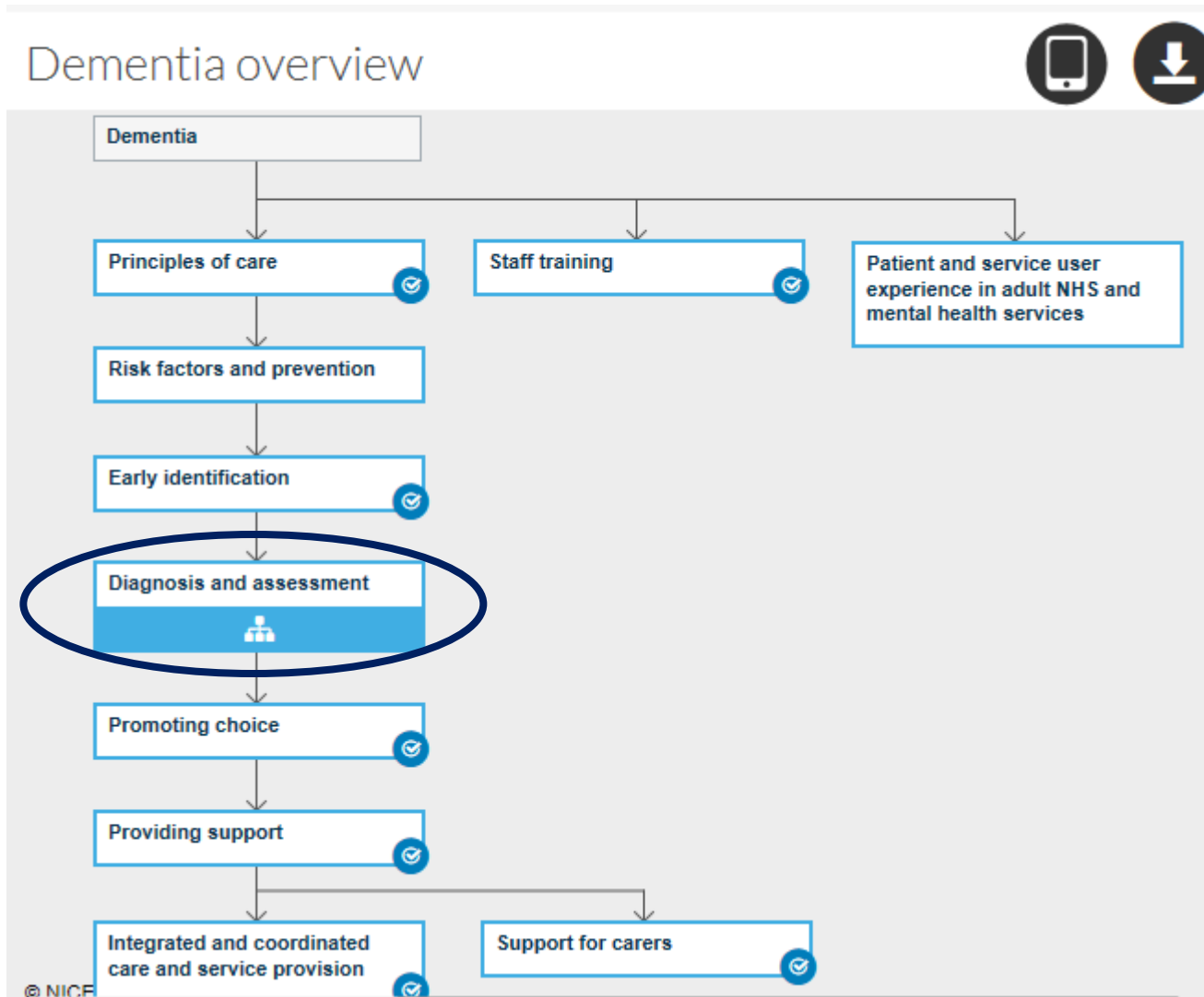
- Low-dose anti-psychotics in people with dementia
- Management of aggression, agitation and behavioural disturbances in dementia: carbamazepine, and valproate preparations

Mid-life approaches to prevention

- Published October 2015
- Covers service delivery and healthy lifestyles
- Evidence for association with lifestyle factors:

Lifestyle factors	Direction of association with dementia risk
Smoking	↑
Alcohol	→
Nutritional deficiency	→
Physical activity	↓→
Cognitive stimulation	↓

Dementia Pathway: overview

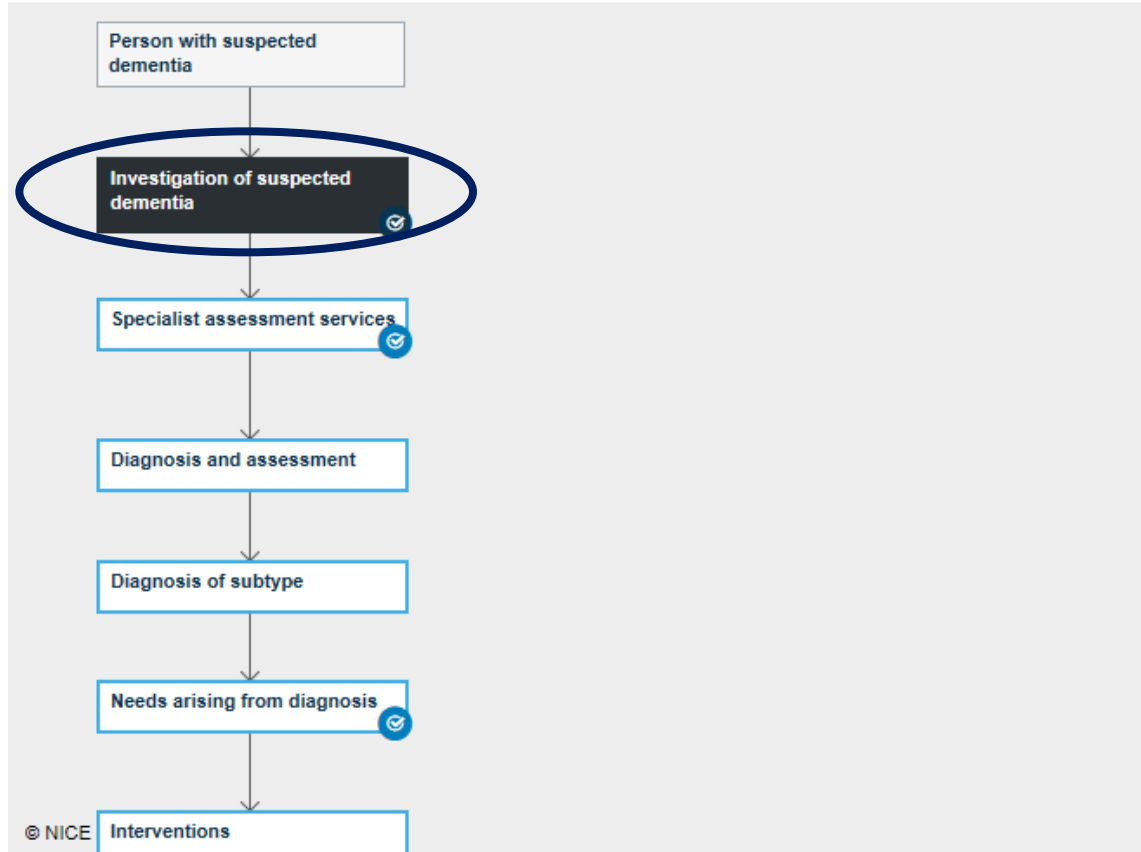


Dementia Pathway: investigations

Dementia diagnosis and assessment



Dementia



Investigation of suspected dementia

Conduct a basic dementia screen at the time of presentation, usually in primary care. Include:

- routine haematology
- biochemistry tests (electrolytes, calcium, glucose, and renal and liver function)
- thyroid function tests
- serum vitamin B₁₂ and folate levels.

Perform a midstream urine test if delirium is a possibility. For more information on delirium, see the NICE pathway on [delirium](#).

Conduct investigations such as chest X-ray or electrocardiogram (ECG) as determined by clinical presentation.

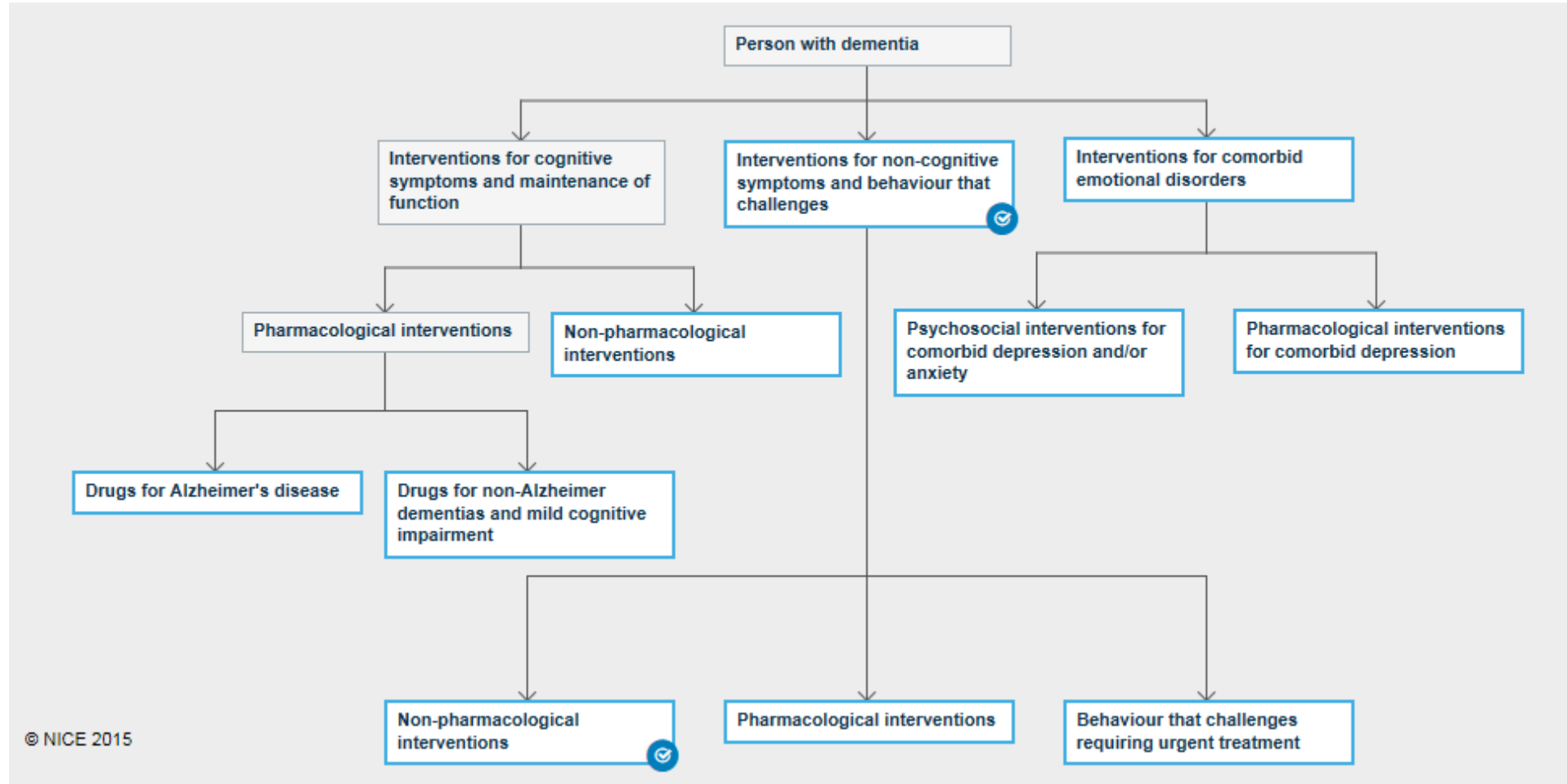
Do not routinely:

- test for syphilis serology or HIV unless there are risk factors or the clinical picture dictates
- examine cerebrospinal fluid.

Quality standards

Dementia Pathway: interventions

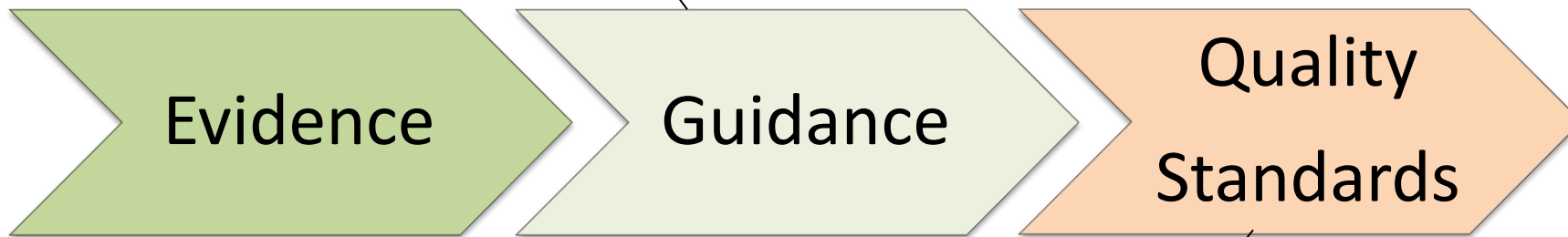
Dementia interventions



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Guidance and quality standards

A comprehensive set of recommendations for a particular condition or service area



'Sentinel markers'

A prioritised set of concise, measurable statements designed to drive quality improvements across a pathway of care.

Quality standards and dementia

- **Dementia** – focus on healthcare
- **Supporting people to live well with dementia** – social care quality standard - focus on experience of care
- **Together form a comprehensive set of 20 statements for health and social care**
- Mental well-being of older people in care homes – may be relevant

Guidance and standards




The standards are based primarily on NICE clinical guidance *Dementia: Supporting people with dementia and their carers in health and social care*. Also informed by the SCIE guide *Dignity in care*.

Dignity in care



SCIE Guide 15
Published: June 2010
Review date: June 2013

The Dignity in Care guide is for people who want to make a difference by improving standards of dignity in care. It provides a wealth of resources and practical guidance to help service providers and practitioners in developing their practice, with the aim of ensuring that all people who receive health and social care services are treated with dignity and respect. The guide can also provide people who use services with information on what to expect from health and social care services. It applies to England only.

You only have five minutes to get some quick ideas, or five hours to gain an in-depth understanding, so this guide should meet your needs.

Factors	Stand up for dignity	Specialist care
		
Factors that define dignity in care.	Law and processes enable people to address the absence of dignity.	Supporting people with mental health problems and people at the end of life.
more	more	more

Overview

Overview	Resources
	
Research says about care.	Practical tools and information to help with training for Dignity in care.
more	more

NICE Clinical Guideline
Dementia: Supporting people with dementia and their carers in health and social care

Issue date: November 2006 (amended March 2011)

Dementia
Supporting people with dementia and their carers in health and social care

This NICE clinical guideline has been amended to incorporate the updated NICE technology appraisal of drugs for Alzheimer's disease, published in March 2011 (www.nice.org.uk/guidance/TA217). See pages 31–33 for the updated information. The rest of the NICE clinical guideline remains unchanged.

NICE Clinical Development

Living well with dementia

A set of 10 statements

Provide a clear focus on the priority areas for continuous improvement in quality and outcomes

To be read alongside the healthcare standard for dementia

Associated with outcome and process measures.

List of quality statements

Quality statement 1: Discussing concerns about possible dementia

Quality statement 2: Choice and control in decisions

Quality statement 3: Reviewing needs and preferences

Quality statement 4: Leisure activities of interest and choice

Quality statement 5: Maintaining and developing relationships

Quality statement 6: Physical and mental health and wellbeing

Quality statement 7: Design and adaptation of housing

Quality statement 8: Planning and evaluating services

Quality statement 9: Independent advocacy

Quality statement 10: Involvement and contribution to the community

Quality statement 4

People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.



‘Enabled’ refers to actions taken by care providers to ensure that people with dementia can take part in leisure activities during their day. This includes, but is not limited to, finding out people's individual interests and preferences, providing daily activities and providing transport.

Quality measures

Structure

Evidence of local arrangements:

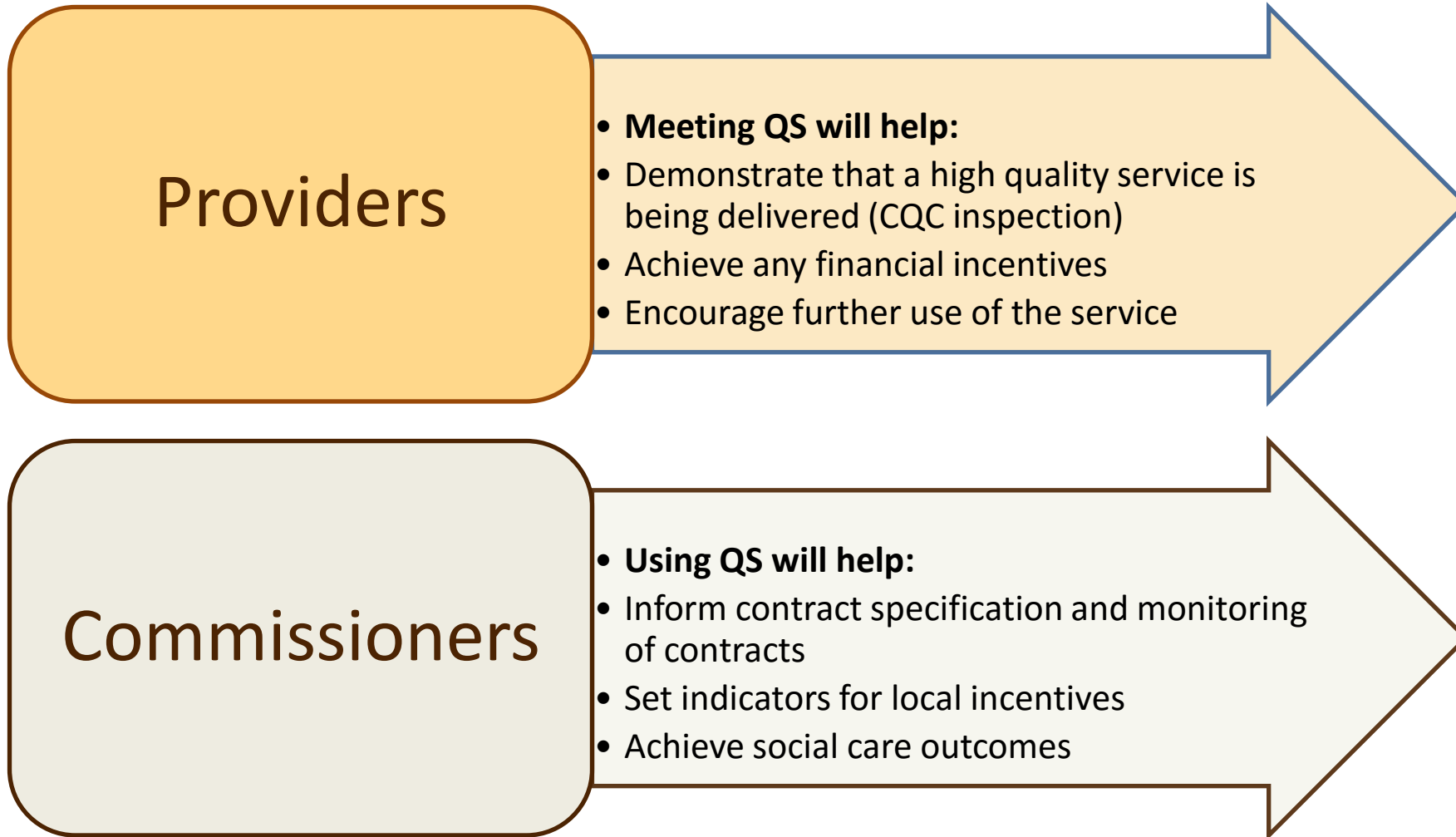
- to find out about individual interests and preferences to ensure access to leisure activities of interest.
- to ensure people with dementia are enabled to take part in leisure activities based on individual interest.

Outcome

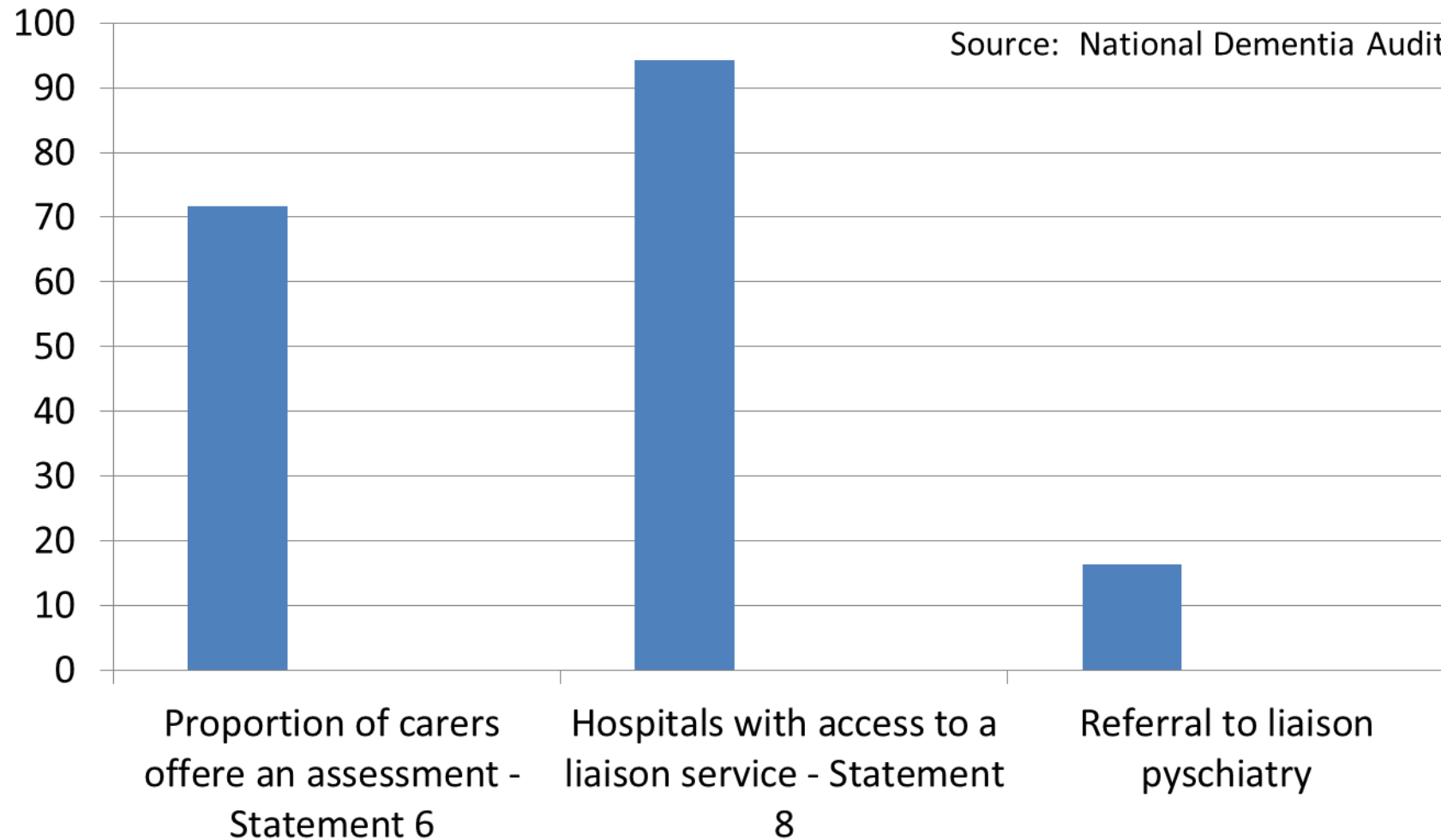
Feedback:

- *from people with dementia* that they take part in leisure activities based on individual interest and choice.
- *from the carers* of people with dementia that the person they support takes part in leisure activities based on individual interest.

Commissioner and provider perspectives

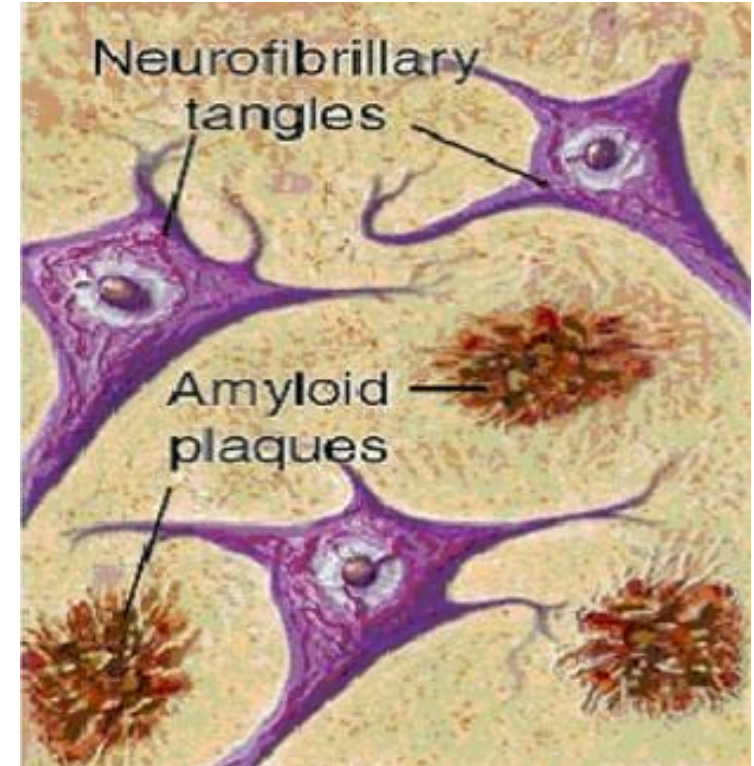


Uptake data: dementia QS



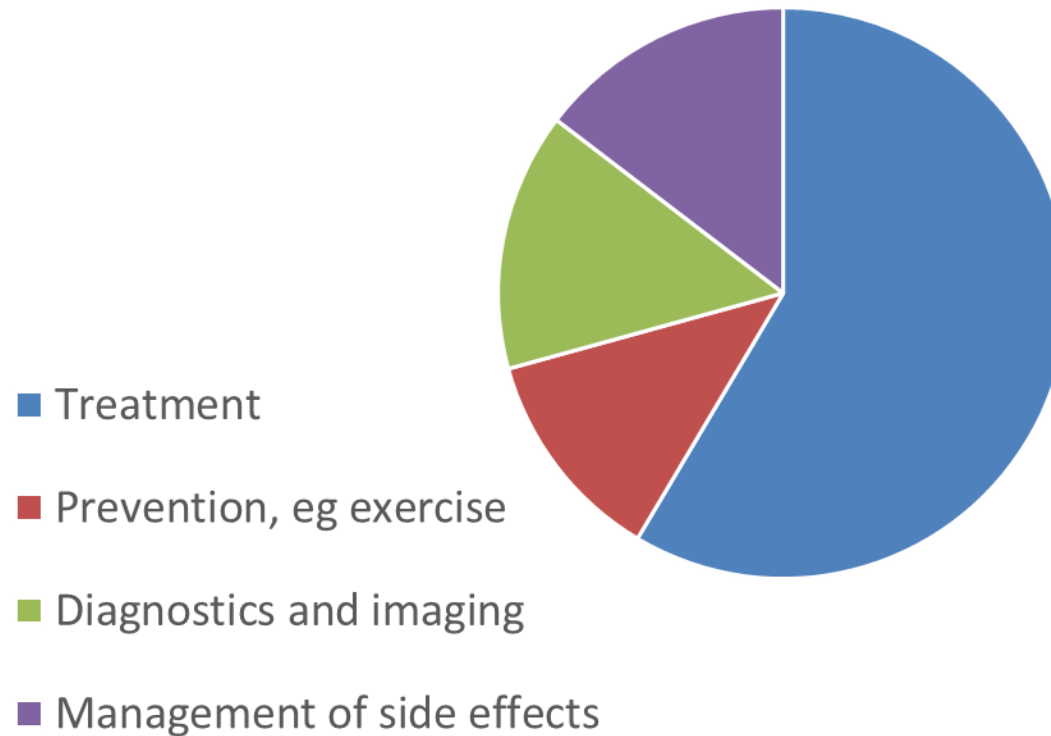
The future – new drugs

- Currently 9 drugs in phase III trials for mild to moderate Alzheimers and 4 for early stage disease
- Mode of action targeted at Amyloid-beta – new mechanisms required?
- Outcomes are cognitive function and activities of daily living
- Some research into asymptomatic patients, from 40 years, who have the potential develop Alzheimers.



Ongoing research

Globally, there are at least 82 ongoing trials



Summary

- NICE guidelines – recommendations on ‘what works’, for organisations that provide, commission and provide services to ensure services are safe, effective and value for money.
- Quality standards – a concise set of statements designed to drive and measure improvement in quality.
- A portfolio of guidance and support relevant to dementia, brought together in NICE Pathways.

