

'Challenges and Opportunities for Dementia & Research in WY&H HCP'



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Bradford City CCG
Bradford Districts CCG

My Declarations of Interest

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Dementia Research

I have dementia and I take part in research. Here's why.

BY WENDY MITCHELL JULY 4, 2017 // 4 COMMENTS



So, as you can see, I have dementia, but **I'm still able to contribute to society.**



Why am I so willing?
Because I like to be involved, because being involved has given me back that sense of purpose that a diagnosis of dementia stripped away from me.

We all had talents before a diagnosis of dementia – we don't suddenly lose all those talents overnight

Being involved makes me feel valued and people listen to what I have to say.....

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**WHO CAN HELP
RESEARCHERS
TO BEAT
DEMENTIA?**



YOU

What are the facts?

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The scale of the challenge

850,000 people living with dementia in the UK

By 2025

over **one million** people could have dementia in the UK

By 2050

this figure will exceed **2 million**

1 in 3

people born in the UK this year will develop dementia in their lifetime.

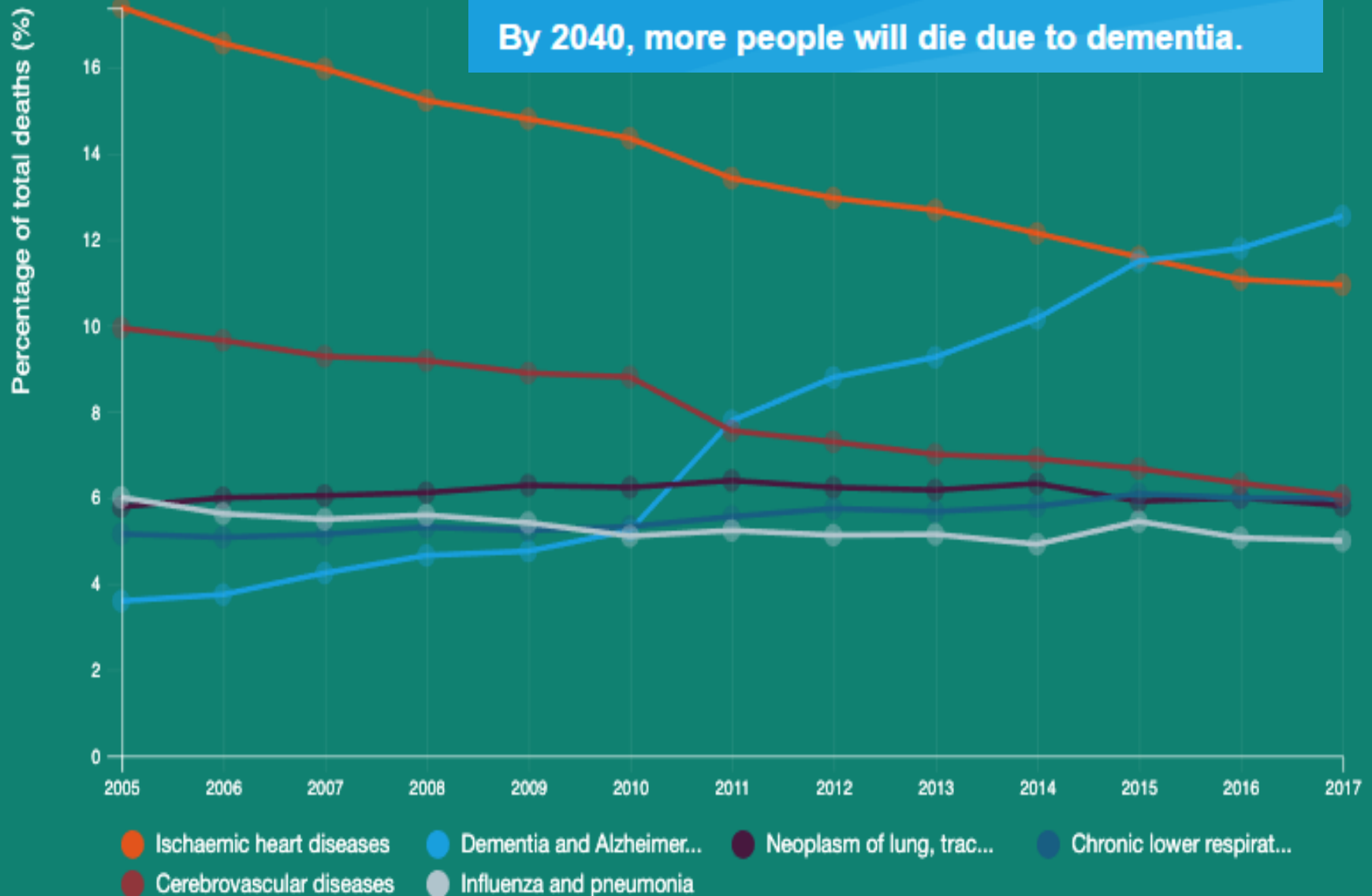
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In 2014, there were more than twice the number of deaths due to all cancers than dementia.

By 2040, more people will die due to dementia.



3.6 Table 2: leading causes of death by age group for males in England, 2015

Leading causes of death vary by age for males

Age	External	Cancer	Circulatory	Respiratory	Other
	1st	2nd	3rd	4th	5th
1-4	Perinatal & congenital	Influenza and pneumonia	Brain cancer	Meningitis and meningococcal infection	Vaccine preventable disease
5-19	Suicide	Transport accidents	Homicide	Leukaemia and lymphomas	Brain cancer
20-34	Suicide	Accidental poisoning	Transport accidents	Homicide	Cirrhosis and other liver disease
35-49	Suicide	Heart disease	Accidental poisoning	Cirrhosis and other liver disease	Stroke
50-64	Heart disease	Lung cancer	Cirrhosis and other liver disease	Colorectal cancer	Chronic lower respiratory diseases
65-79	Heart disease	Lung cancer	Chronic lower respiratory diseases	Stroke	Prostate cancer
80+	Dementia and Alzheimer's disease	Heart disease	Influenza and pneumonia	Stroke	Chronic lower respiratory diseases

3.7 Table 3. Leading causes of death by age group for females in England, 2015

Leading causes of death vary by age for females

Age	External	Cancer	Circulatory	Respiratory	Other
	1st	2nd	3rd	4th	5th
1-4	Perinatal & congenital	Homicide	Influenza and pneumonia	Septicaemia	Other acute respiratory diseases
5-19	Suicide	Transport accidents	Perinatal & congenital	Leukaemia and lymphomas	Brain cancer
20-34	Suicide	Accidental poisoning	Transport accidents	Breast cancer	Cirrhosis and other liver disease
35-49	Breast cancer	Cirrhosis and other liver disease	Accidental poisoning	Suicide	Heart disease
50-64	Lung cancer	Breast cancer	Heart disease	Chronic lower respiratory diseases	Cirrhosis and other liver disease
65-79	Lung cancer	Chronic lower respiratory diseases	Heart disease	Dementia and Alzheimer's disease	Stroke
80+	Dementia and Alzheimer's disease	Heart disease	Stroke	Influenza and pneumonia	Chronic lower respiratory diseases



In the UK, dementia is the only condition in the top 10 causes of death without a treatment to prevent, cure or slow its progression.



Source: England and Wales; Mortality Statistics: Deaths Registered in England and Wales (Series DR) Scotland: National Records of Scotland Vital Events Reference Tables. Northern Ireland; Northern Ireland Statistic & Research Agency Registrar General Annual Report

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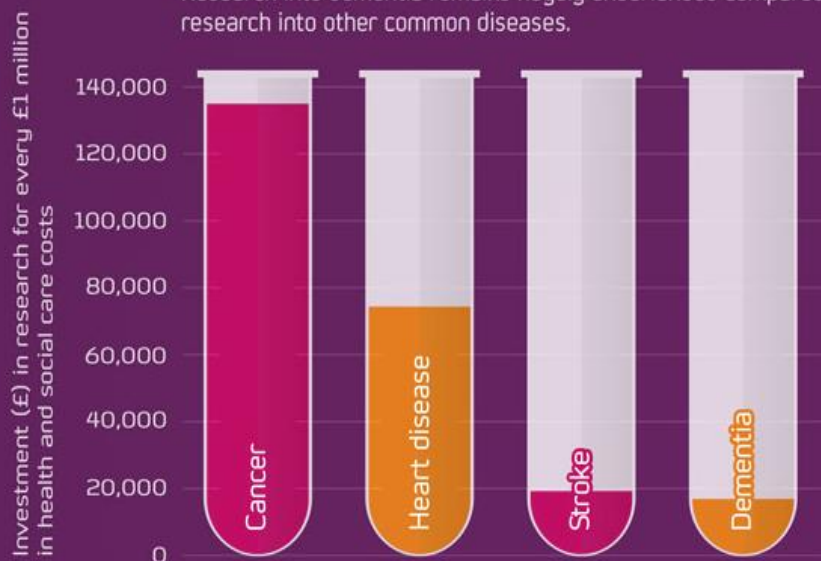
Now the facts about Dementia Research

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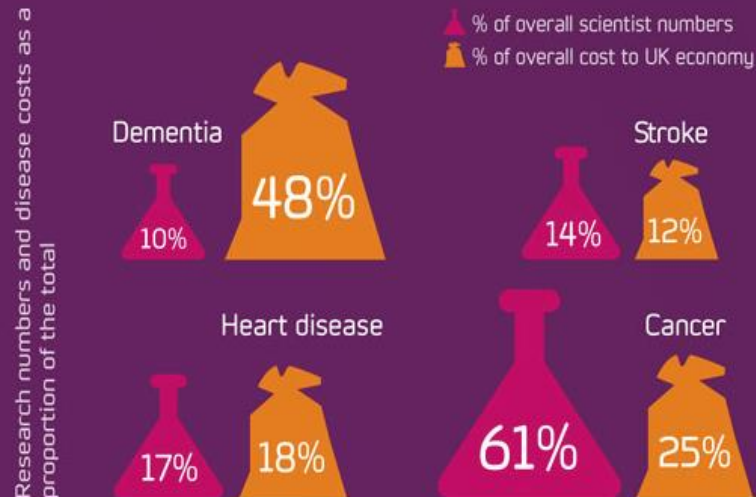
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Dementia research in numbers

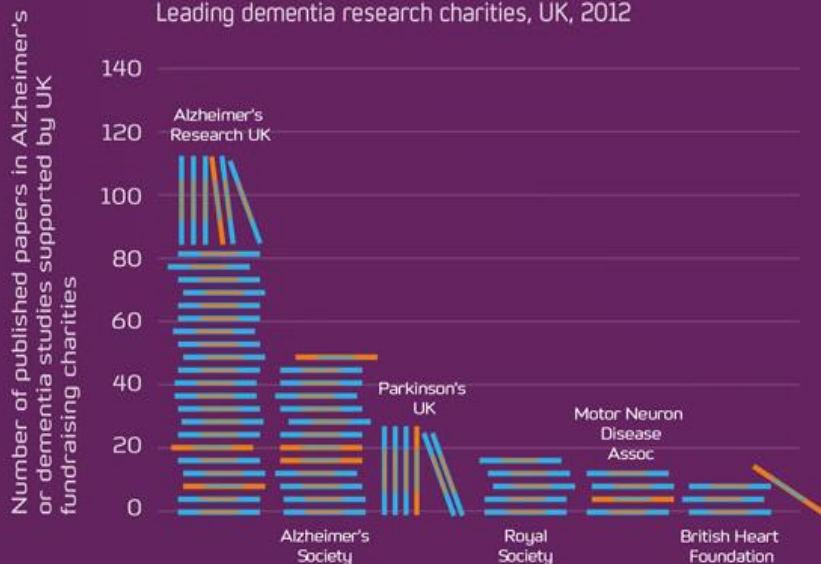
Research into dementia remains hugely underfunded compared to research into other common diseases.



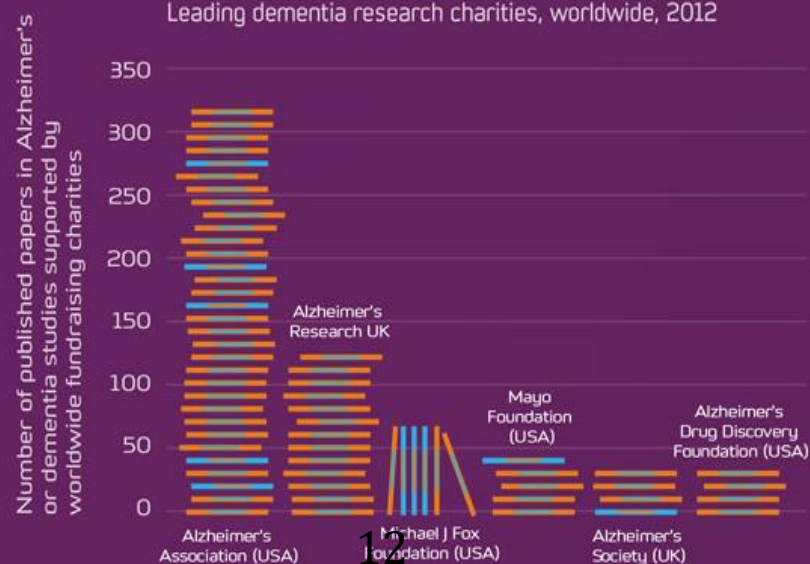
There are an estimated 4,061 dementia researchers in the UK (28,062 for cancer, 6,433 for heart disease, 4,784 for stroke).



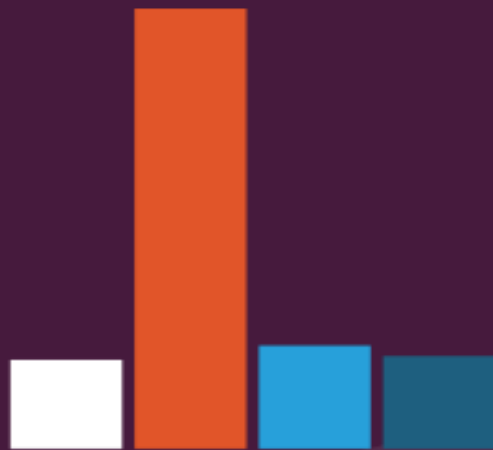
Leading dementia research charities, UK, 2012



Leading dementia research charities, worldwide, 2012



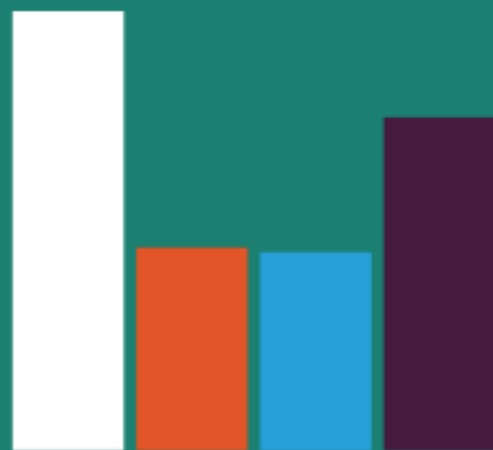
In 2014/15 there were 3,169 dementia papers published, 15,697 in cancer, 3,678 in coronary heart disease and 3,304 in stroke.



Alzheimer's
Research
UK



The number of UK researchers has risen by **91%** in dementia, by **42%** in cancer, **41%** in coronary heart disease and by **69%** in stroke between 2008/09 and 2014/15.



Alzheimer's
Research
UK

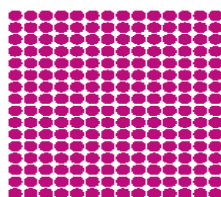




Join Dementia Research in numbers



30,145
total volunteers



56,956
screenings



7,888
participants that have enrolled
in studies to date



26%
of volunteers have
participated in a study



165
Studies have recruited



108
Studies currently open
to recruitment



852
trained researchers
using the service



176
NHS, University & commercial sites
have used the system

What are the National drivers in Dementia Care ?

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National Dementia Strategy 2009

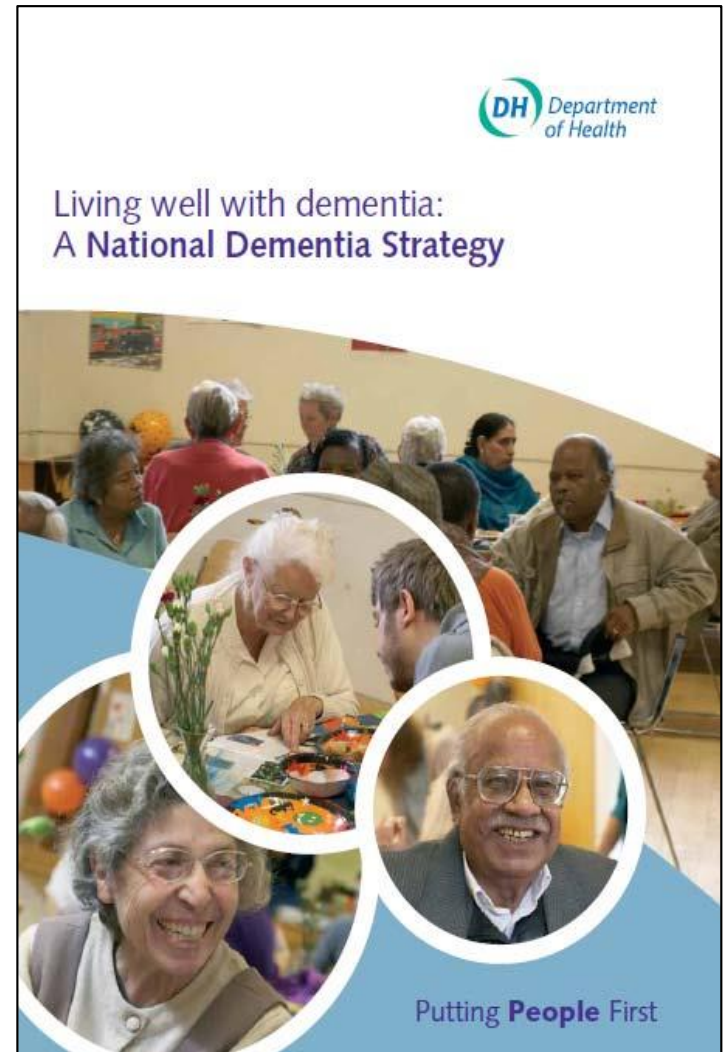
- 5 year plan
- 17 interlinked objectives
- £150million extra funding

Key themes

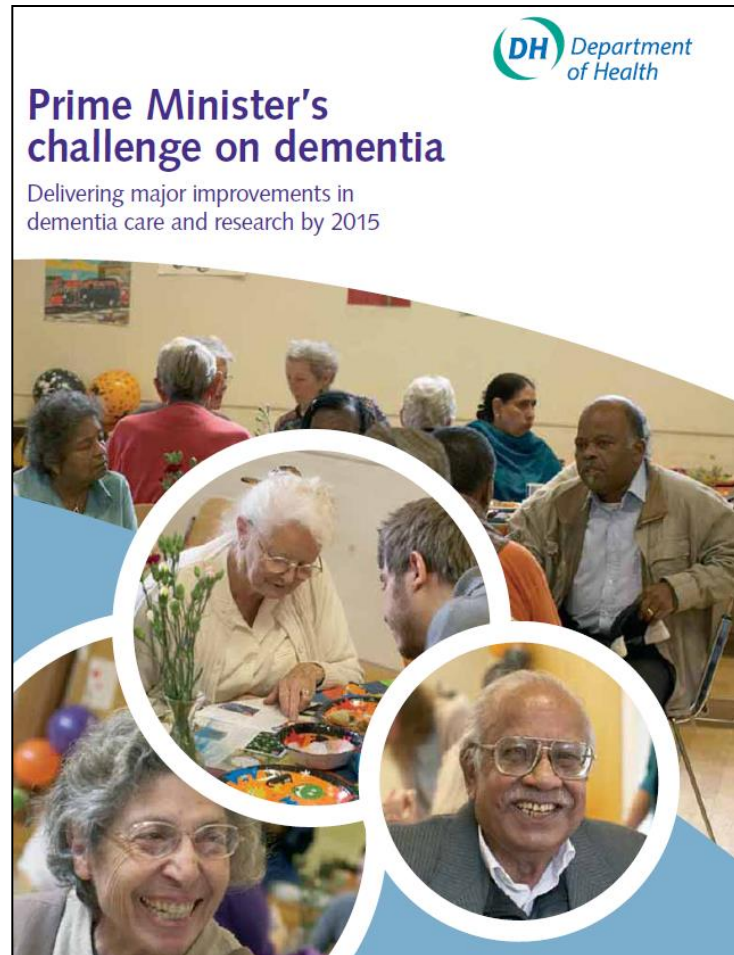
- Improving awareness
- Early and better diagnosis
- Improved quality of care
- Delivering the Strategy

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Prime Minister's challenge on dementia 2012



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Prime Minister's challenge on dementia 2020



February 2015

Awareness
Key role of GPs
Post diagnostic support
 Information, advice, carers
Access to diagnosis
Staff training
Dementia Institute
Dementia Friends/ businesses
Advance Care Planning
Research

1 million dementia friends
Highest diagnosis rate

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1: Enhancing quality of life for people with care and support needs	2: Delaying and reducing the need for care and support	3: Ensuring people have a positive experience of care and support	4: Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm
<p>Overarching measures</p> <p>1A. Social care-related quality of life</p> <p>1J – Adjusted Social care-related quality of life – impact of Adult Social Care Services</p> <p>Outcome measures</p> <p><i>People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs</i></p>	<p>Overarching measure</p> <p>2A. Long-term support needs met by admission to residential and nursing care homes, per 100,000 population</p> <p>Outcome measures</p> <p><i>Everybody has the opportunity to have the best health and wellbeing throughout their life, and</i></p>	<p>Overarching measures</p> <p><i>People who use social care and their carers are satisfied with their experience of care and support services</i></p> <p>3A. Overall satisfaction of people who use services with their care and support</p> <p>3B. Overall satisfaction of carers with social</p>	<p>Overarching measure</p> <p>4A. Proportion of people who use services who feel safe</p> <p>Outcome measures</p> <p><i>Everyone enjoys physical activity and feels secure People are free from physical and emotional abuse, harassment, neglect and self-harm People are protected as far as possible from</i></p>

Appendix 3 – The Public Health Outcomes Framework 2016-19 at a glance

VISION
To improve and protect the nation's health and wellbeing and improve the health of the poorest fastest
Outcome measures
Outcome 1) Increased healthy life expectancy, i.e. taking account of the health quality as well as the length of life
Outcome 2) Reduced differences in life expectancy and healthy life expectancy between communities (through greater improvements in more disadvantaged communities)

Alignment across the Health and Care System

- ** Indicator shared with the NHS Outcomes Framework.
- ** Complementary to indicators in the NHS Outcomes Framework
- † Indicator shared with the Adult Social Care Outcomes Framework
- †† Complementary to indicators in the Adult Social Care Outcomes Framework

Indicators in italics are placeholders, pending development or identification

Public Health Outcomes Framework 2016-2019 At a glance

- 1B. Proportion of people who use services have control over their daily life
- 1C. Proportion of people using social care receive self-directed support, and those receiving direct payments
- Carers can balance their caring roles and maintain their desired quality of life*
- 1D. Carer-reported quality of life
- People are able to find employment where they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation*
- 1E. Proportion of adults with a learning disability in paid employment
- 1F. Proportion of adults in contact with secondary mental health services in paid employment
- 1G. Proportion of adults with a learning disability who live in their own home or with their family
- 1H. Proportion of adults in contact with secondary mental health services living independently, with or without support
- 1I. Proportion of people who use services carers, who reported that they had as much social contact as they would like

1 Improving the wider determinants of health
Objective
Improvements against wider factors which affect health and wellbeing and health inequalities
Indicators
1.1 Children in low income families
1.2 School readiness
1.3 Pupil absence
1.4 First time entrants to the youth justice system
1.5 16-18 year olds not in education, employment or training
1.6 Adults with a learning disability / in contact with secondary mental health services who live in stable and appropriate accommodation* (ASCOF 1G and 1H)
1.7 Proportion of people in prison aged 18 or over who have a mental illness
1.8 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services (NHSOF 2.2) ††(ASCOF 1E) ††(NHSOF 2.5) ††(ASCOF 1F)
1.9 Sickness absence rate
1.10 Killed and seriously injured casualties on England's roads
1.11 Domestic abuse
1.12 Violent crime (including sexual violence)
1.13 Levels of offending and re-offending
1.14 The percentage of the population affected by noise
1.15 Statutory homelessness
1.16 Utilisation of outdoor space for exercise / health reasons
1.17 Fuel poverty
1.18 Social isolation* (ASCOF 1I)

2 Health improvement
Objective
People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities

3 Health protection
Objective
The population's health is protected from major incidents and other threats, whilst reducing health inequalities

4 Healthcare public health and preventing premature mortality
Objective
Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities

Appendix 2 – NHS Outcomes Framework 2017/18 – at a glance

1 Preventing people from dying prematurely
Overarching indicators
1a Potential years of life lost (PYLL) from causes considered amenable to healthcare * Adults * † Children and young people † Life expectancy at 75 † Males * † Females * † National mortality and stillbirths
Improvement areas
<p>Reducing premature mortality from the major causes of death</p> <p>1.1 Under 75 mortality rate from cardiovascular disease (PHOF 4.1)* †</p> <p>1.2 Under 75 mortality rate from respiratory disease (PHOF 4.2)* †</p> <p>1.3 Under 75 mortality rate from liver disease (PHOF 4.3)* †</p> <p>1.4 Under 75 mortality rate from cancer (PHOF 4.4)* †</p> <p>1.5 One- and † Five-year survival from all cancers</p> <p>1.6 One- and † Five-year survival from breast, lung and colorectal cancer</p> <p>1.7 One- and † Five-year survival from cancers diagnosed at stage 1&2 (PHOF 2.1)** †</p> <p>Reducing premature mortality in people with mental illness</p> <p>1.8 Excess under 75 mortality rate in adults with serious mental illness (PHOF 4.5)* †</p> <p>1.9 Excess under 75 mortality rate in adults with common mental illness</p> <p>1.10 Suicide and mortality from injury of undetermined intent among people with recent contact from NHS services (PHOF 4.6)** †</p> <p>Reducing mortality in children</p> <p>1.11 Infant mortality (PHOF 4.7)* †</p> <p>1.12 Five year survival from all cancers in children</p> <p>Reducing premature death in people with a learning disability</p> <p>1.13 Excess under 60 mortality rate in adults with a learning disability</p>
2 Enhancing quality of life for people with long-term conditions
Overarching indicators
2 Health-related quality of life for people with long-term conditions (ASCOF 1A)** †
Improvement areas
<p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition (PHOF 1.8)** †</p> <p>Improving functional ability in people with long-term conditions</p> <p>2.2 Employment of people with long-term conditions (ASCOF 1C)** †</p> <p>Reducing time spent in hospital by people with long-term conditions</p> <p>2.3 Unplanned hospitalisation for chronic ambulatory care sensitive conditions * †</p> <p>2.4 Unplanned hospitalisation for asthma, diabetes and epilepsy in under 15s</p> <p>Enhancing quality of life for carers</p> <p>2.5 Health-related quality of life for carers (ASCOF 1D)** †</p> <p>Enhancing quality of life for people with mental illness</p> <p>2.6 Employment of people with mental illness (ASCOF 1E)** †</p> <p>2.7 Health-related quality of life for people with mental illness (ASCOF 1A)** †</p> <p>2.8 PHOF 1.9** †</p> <p>Enhancing quality of life for people with dementia</p> <p>2.9 Estimated dementia care for people with dementia (PHOF 4.10)* †</p> <p>2.10 A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life (ASCOF 2C)** †</p> <p>Improving quality of life for people with multiple long-term conditions</p> <p>2.11 Health-related quality of life for people with three or more long-term conditions (ASCOF 1A)** †</p>

3 Helping people to recover from episodes of ill health or following injury
Overarching indicators
3a Emergency admissions for acute conditions that should not usually require hospital admission * †
3b Emergency readmissions within 30 days of discharge from hospital (PHOF 4.11)* †
Improvement Areas
<p>Improving outcomes from planned treatments</p> <p>3.1 Total health gain as assessed by patients for elective procedures</p> <ul style="list-style-type: none"> Physical health-related procedures Psychological therapies Recovery in quality of life for patients with mental illness <p>Preventing lower respiratory tract infections (LRTI) in children from becoming serious</p> <p>3.2 Emergency admissions for children with LRTI</p> <p>Improving recovery from injuries and trauma</p> <p>3.3 Survival from major trauma</p> <p>Improving recovery from stroke</p> <p>3.4 Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months</p> <p>Improving recovery from fragility fractures</p> <p>3.5 Proportion of patients with hip fractures, recovering to their previous levels of mobility/walking ability at 30 and † 120 days</p> <p>3.6 Proportion of patients with hip fractures, recovering to their previous levels of mobility/walking ability at 30 and † 120 days</p> <p>Helping older people to recover their independence after illness or injury</p> <p>3.7 Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into replacement/rehabilitation service (ASCOF 2B)** †</p> <p>3.8 Proportion of older people who were still at home 91 days after discharge from hospital into replacement/rehabilitation service (ASCOF 2B)** †</p> <p>Improving Dental Health</p> <p>3.9 3.7 † Decaying teeth (PHOF 4.02)** †</p> <p>3.8 Tooth extractions in secondary care for children under 10</p>

4 Ensuring that people have a positive experience of care
Overarching indicators
4a Patient experience of primary care
4b Patient experience of out-patient services
4c GP Out-of-hours services
4d NHS dental services
4e Patient experience of hospital care
4f Friends and family test
4g Patient experience characterised as poor or worse
4h Primary care
4i Hospital care
Improvement areas
<p>Improving people's experience of outpatient care</p> <p>4.1 Patient experience of outpatient services</p> <p>Improving hospital's responsiveness to personal needs</p> <p>4.2 Responsiveness to in-patient personal needs</p> <p>Improving people's experience of accident and emergency services</p> <p>4.3 Patient experience of A&E services</p> <p>Improving access to primary care services</p> <p>4.4 Access to GP services * and † NHS dental services</p> <p>Improving women and their families' experience of maternity services</p> <p>4.5 Women's experience of maternity services</p> <p>Improving the experience of care for people at the end of their lives</p> <p>4.6 Bereaved carers' views on the quality of care in the last 3 months of life</p> <p>Improving experience of healthcare for people with mental illness</p> <p>4.7 Patient experience of community mental health services</p> <p>Improving children and young people's experience of healthcare</p> <p>4.8 Children and young people's experience of inpatient services</p> <p>Improving people's experience of integrated care</p> <p>4.9 People's experience of integrated care (ASCOF 3E)** †</p>

NHS Outcomes Framework 2017/18 at a glance

Alignment with Adult Social Care Outcomes Framework (ASCOF) and/or Public Health Outcomes Framework (PHOF)

- ** Indicator is shared
- ** Indicator is complementary
- † Indicator is for health inequalities assessment
- † Indicators in italics are in development

5 Treating and caring for people in a safe environment and protecting them from avoidable harm
Overarching indicators
5a Deaths attributable to problems in healthcare
5b Severe harm attributable to problems in healthcare
Improvement areas
<p>Reducing the incidence of avoidable harm</p> <p>5.1 Deaths from venous thromboembolism (VTE) related events</p> <p>5.2 Incidence of healthcare associated infection (HCAI) (NHSA)</p> <p>5.3 C. difficile</p> <p>5.4 Hip fractures from falls during hospital care</p> <p>5.5 Proportion of patients with category 2, 3 and 4 pressure ulcers</p> <p>Improving the safety of maternity services</p> <p>5.6 Admission of full-term babies to neonatal care</p> <p>Improving the culture of safety reporting</p> <p>5.7 Patient safety incidents reported</p>

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NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾, BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾, Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾, Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL

- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

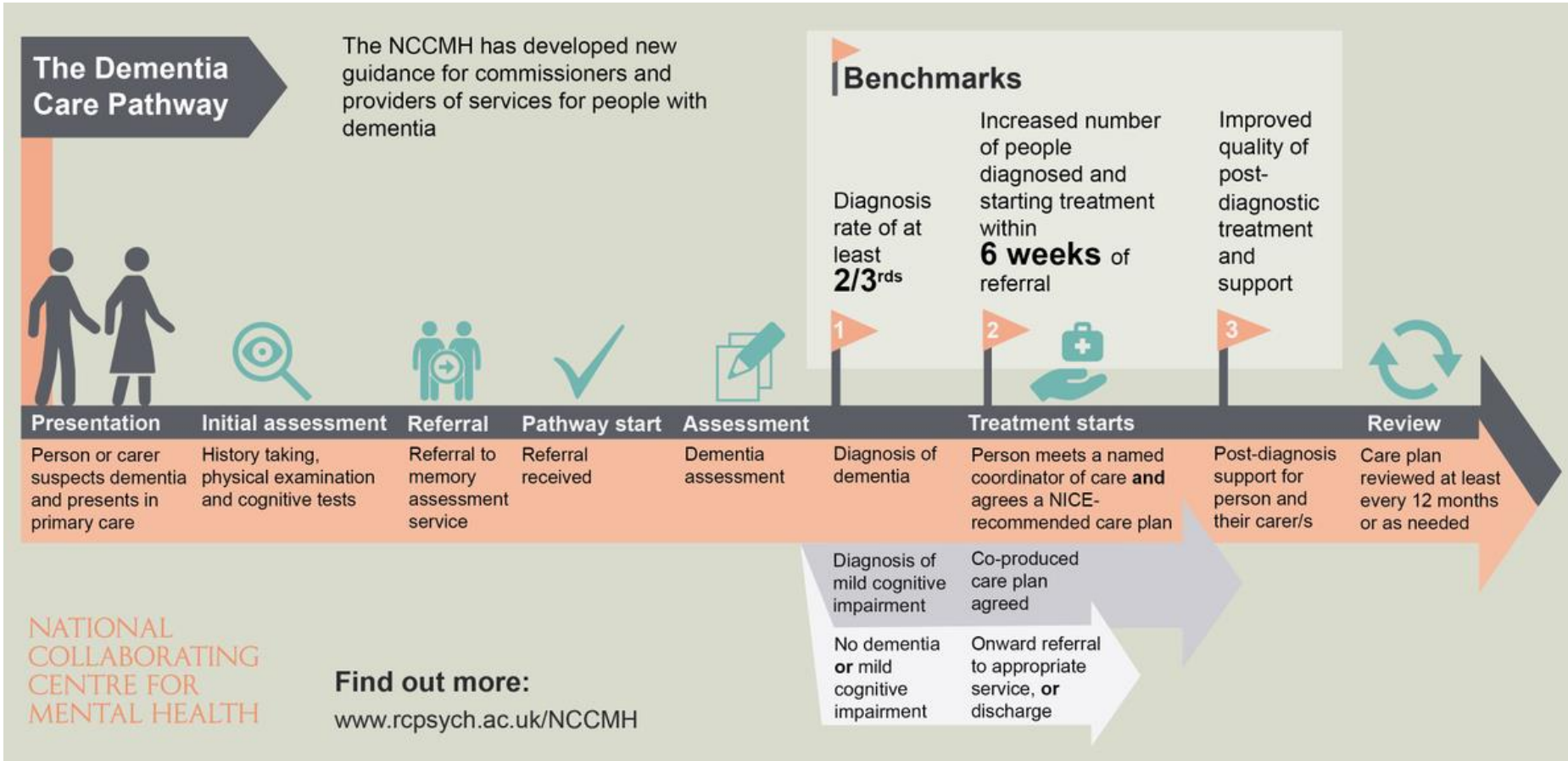
TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

What does the journey look like?



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What does good dementia care look like?

	Key statements
"I was diagnosed in a timely way"	We know that if I am referred for an assessment for dementia, I will receive a timely diagnosis and agree on an initial care plan.
"I am able to make decisions, and I know what to do to help myself and who else can help"	<p>We know that I will have a personal choice in decisions affecting my care and support.</p> <p>We know that I will be able to jointly develop my care plan.</p> <p>We know that if I need help, I will be supported to make a decision, for example through the use of independent advocacy services.</p>
"I am treated with dignity and respect"	<p>We know that services are designed around us and our needs, and that they will be appropriately staffed and staff will have the right levels of training.</p> <p>We know that services will provide the best possible care, and will be regularly reviewed by other agencies.</p>
"I get treatment and support which are best for my dementia and my life"	Once I am diagnosed, we know that we will have a named coordinator of care who will jointly review my care plan with us as our needs change. This will happen at least once a year.
"Those around me and looking after me are supported"	<p>We know that my care plan will cover my own needs as well as those of the people who support me. This will include our emotional, psychological and social needs.</p> <p>We know that a carer's assessment will be offered.</p>
"I feel included as part of society"	We know that my care plan will give us the support we need to live well. This may include helping me build relationships, be involved in my community or engage in activities that I enjoy.
"I am confident my end-of-life wishes will be respected and I can expect a good death"	We know that my care plan will help us to plan for the future, including my end-of-life wishes.

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“i” statements

- I have personal choice and control over the decisions that affect me.
- I know that services are designed around me, my needs and my carer’s needs.
- I have support that helps me live my life.
- I have the knowledge to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I am confident my end of life wishes will be respected. I can expect a good death.
- ***I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.***

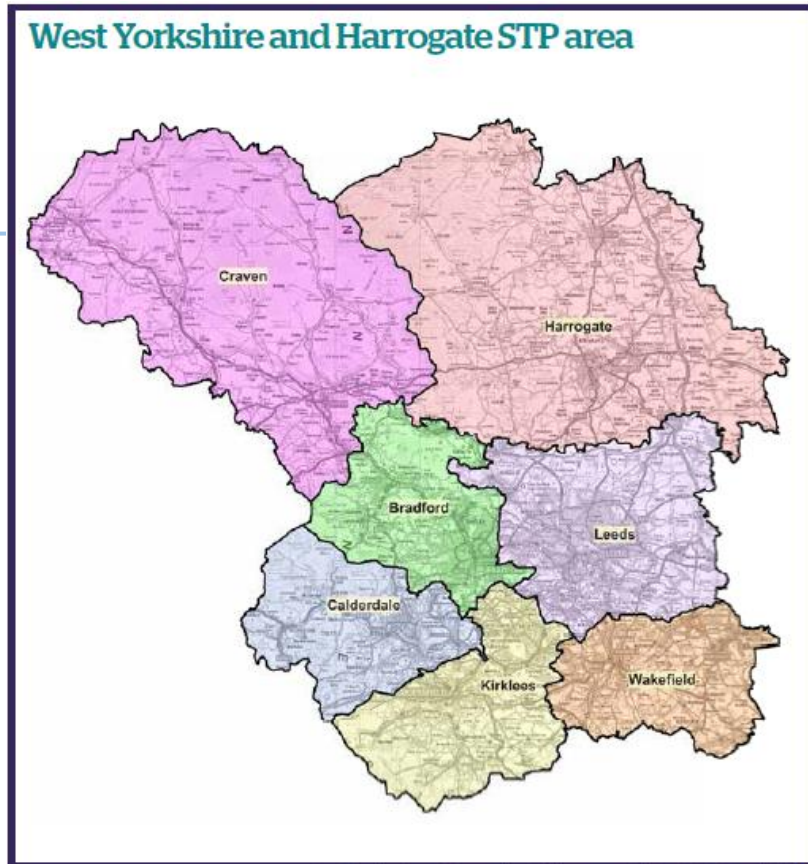
What are the more local drivers ?

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West Yorkshire and Harrogate Health & Care Partnership

Six local area plans.....



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- Bradford District & Craven
- Calderdale
- Harrogate & Rural District
- Kirkstoes
- Leeds
- Wakefield

Covering prevention, primary care, and joined up health and social care services.

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Based around the relationships of the Health and Wellbeing Boards and Health and Wellbeing Strategies.

Made up of....

- **It starts with people....2.6 million**

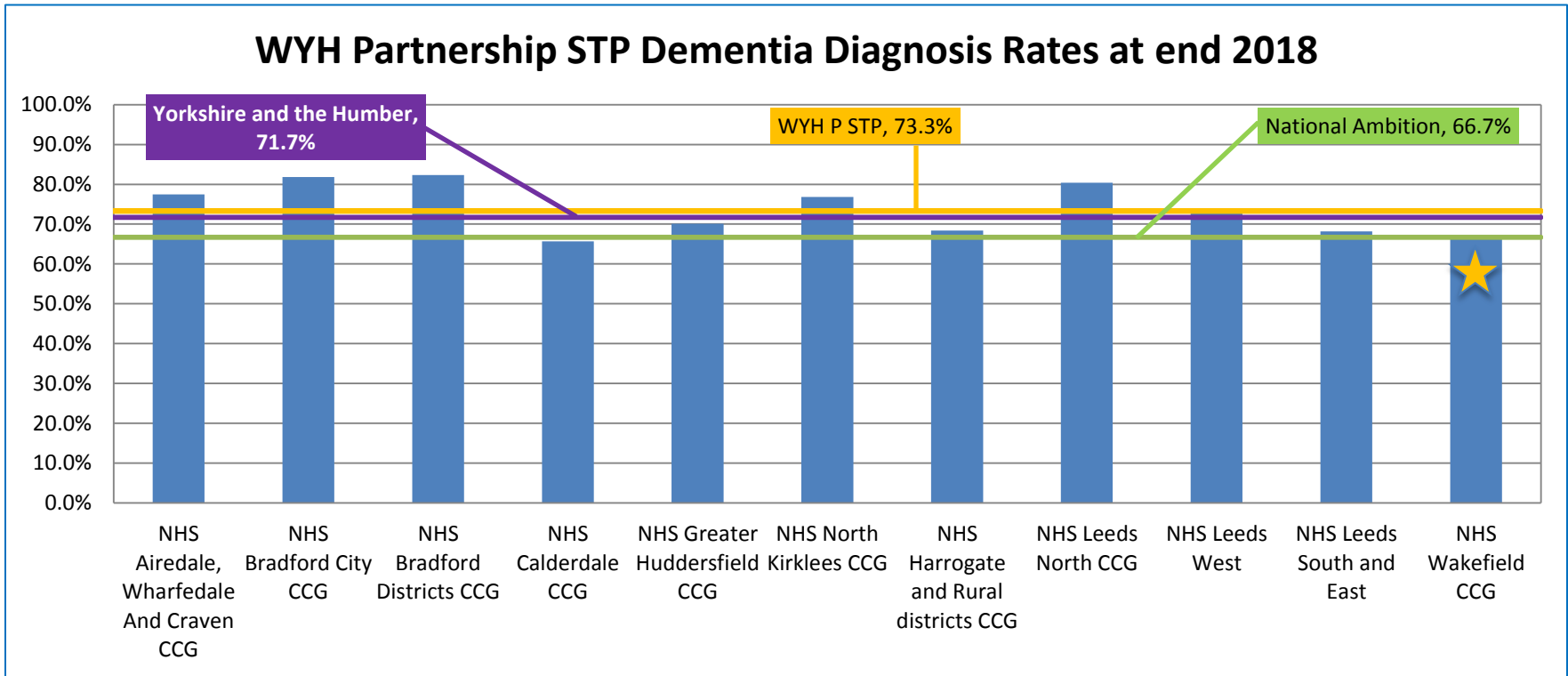
- 11 Clinical Commissioning Groups (6 management teams)
- 8 councils (including 1 county, 5 metropolitan councils, 2 districts)
- 6 hospital trusts, 4 community & mental health trusts
- A number of large independent sector providers,
- Yorkshire Ambulance Service
- 333 GP practices
- 601 community pharmacies
- Over 665 care homes
- 319 domiciliary care providers
- 10 hospices
- Thousands of voluntary and community organisations.

What are Successes!

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Dementia Diagnosis Rates (DDR) end 2018



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Diagnosing Well

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Compared with benchmark:

Better
Similar
Worse
Lower
Similar
Higher
Not compared

Display

Values

Trends

Values & Trends



Export table as image



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Indicator	Period	England	West Yorkshire	NHS Airedale, Wharfedale And Craven...	NHS Bradford City CCG	NHS Bradford Districts CCG	NHS Calderdale CCG	NHS Greater Huddersfield CCG	NHS Harrogate And Rural District...	NHS Leeds CCG	NHS North Kirklees CCG	NHS Wakefield CCG
Dementia: Blood tests recorded at diagnosis	2017/18	68.0	76.3	83.9	82.7	83.3	75.3	69.9	73.9	73.9	66.7	80.6
Estimated dementia diagnosis rate (aged 65 and over)	2018	67.5	72.8	76.9	83.7	81.3	65.5	69.6	76.5	73.6	68.1	67.1
		≥ 66.7% (significantly)	similar to 66.7%	≥ 66.7% (significantly)	≥ 66.7% (significantly)	≥ 66.7% (significantly)	similar to 66.7%	≥ 66.7% (significantly)	≥ 66.7% (significantly)	similar to 66.7%	similar to 66.7%	similar to 66.7%
		< 66.7% (significantly)	< 66.7% (significantly)	≥ 66.7% (significantly)	≥ 66.7% (significantly)	≥ 66.7% (significantly)	< 66.7% (significantly)	≥ 66.7% (significantly)	≥ 66.7% (significantly)	< 66.7% (significantly)	< 66.7% (significantly)	< 66.7% (significantly)

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Living Well

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Compared with benchmark:

Lower
Similar
Higher
Not compared

Display

Values

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Values & Trends



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Indicator	Period	England	West Yorkshire	NHS Airedale, Wharfedale And Crave...	NHS Bradford City CCG	NHS Bradford Districts CCG	NHS Calderdale CCG	NHS Greater Huddersfield CCG	NHS Harrogate And Rural District...	NHS Leeds CCG	NHS North Kirklees CCG	NHS Wakefield CCG
Dementia care review documented in the last 12 months	2017/18	77.5	78.9	79.9	76.4	79.5	74.8	81.4	79.2	79.3	78.2	77.8

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But we have our Challenges !

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Supporting Well

Compared with benchmark: Better Similar Worse Lower Similar Higher Not compared * a note is attached to the value, hover over to see m

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Indicator	Period	England	West Yorkshire	NHS Airedale, Wharfedale And Crave...	NHS Bradford City CCG	NHS Bradford Districts CCG	NHS Calderdale CCG	NHS Greater Huddersfield CCG	NHS Harrogate And Rural District...	NHS Leeds CCG	NHS North Kirklees CCG	NHS Wakefield CCG
Dementia: Quality rating of residential care and nursing home beds (aged 65 years and over)	2018	68.6	54.8	82.9	55.8	53.4	54.3	48.3	56.8	48.7	54.2	49.9
Dementia: Residential care and nursing home bed capacity (aged 65 years and over)	2018	68.2	66.6	80.9	102.4	72.7	58.2	54.3	79.0	57.6	54.9	76.1
Dementia: Percentage of assessed residential care and nursing home beds (aged 65 years and over)	2018	94.1	91.3	92.1	100	95.0	84.1	90.6	87.5	92.8	100	86.0
Dementia: Ratio of inpatient service use to recorded diagnoses - CCG responsibility	2017/18	56.5	55.3	43.1	43.4	54.5	69.1	56.3	43.3	57.2	55.5	61.1
Dementia: Direct standardised rate of emergency admissions (aged 65 years and over) - CCG responsibility	2017/18	3609	3898	2869	4183	4173	4893	3934	2940	4041	3550	4075
Dementia: Short stay emergency admissions (aged 65 years and over) - CCG responsibility	2017/18	28.9	30.4	25.3	47.8	43.7	37.1	39.7	27.8	24.0	29.2	23.1
Alzheimer's disease: Direct standardised rate of inpatient admissions (aged 65 years and over) - CCG responsibility	2017/18	702	850	460	303*	674	737	666	810	1042	868	1097
Vascular dementia: Direct standardised rate of inpatient admissions (aged 65 years and over) - CCG responsibility	2017/18	527	559	809	595	568	771	650	415	539	387	436
Unspecified dementia: Direct standardised rate of inpatient admissions (aged 65 years and over) - CCG responsibility	2017/18	1279	1359	832	1649	1651	1761	1528	914	1213	1507	1552

Dementia: Direct standardised rate of emergency admissions (aged 65 years and over) - CCG responsibility 2017/18



Directly standardised rate - per 100,000

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	–	368,044	3,609	3,598	3,621
West Yorkshire	–	16,600	3,898	3,838	3,958
NHS Airedale, Wharfedale ...	–	1,004	2,869	2,694	3,053
NHS Bradford City CCG	–	320	4,183	3,731	4,673
NHS Bradford Districts CCG	–	2,147	4,173	3,998	4,354
NHS Calderdale CCG	–	1,761	4,893	4,667	5,128
NHS Greater Huddersfield...	–	1,574	3,934	3,741	4,134
NHS Harrogate And Rural ...	–	1,099	2,940	2,768	3,120
NHS Leeds CCG	–	5,216	4,041	3,931	4,153
NHS North Kirklees CCG	–	999	3,550	3,332	3,778
NHS Wakefield CCG	–	2,480	4,075	3,915	4,239

Dementia: Short stay emergency admissions (aged 65 years and over) - CCG responsibility 2017/18

Proportion - %

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	–	115,125	28.9	28.8	29.1
West Yorkshire	–	5,352	30.4	29.7	31.1
NHS Airedale, Wharfedale ...	–	296	25.3	22.9	27.9
NHS Bradford City CCG	–	166	47.8	42.6	53.1
NHS Bradford Districts CCG	–	1,018	43.7	41.7	45.8
NHS Calderdale CCG	–	667	37.1	34.9	39.4
NHS Greater Huddersfield...	–	652	39.7	37.4	42.1
NHS Harrogate And Rural ...	–	313	27.8	25.2	30.5
NHS Leeds CCG	–	1,275	24.0	22.9	25.2
NHS North Kirklees CCG	–	323	29.2	26.6	32.0
NHS Wakefield CCG	–	642	23.1	21.6	24.7

Dying Well

Compared with benchmark:

Better
Similar
Worse
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Not compared

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Display
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Direct standardised rate of mortality: People with dementia (aged 65 years and over)	2017/18	903	959	1084	1307	944	978	908	861	947	865	1011
Deaths in Usual Place of Residence: People with dementia (aged 65 years and over)	2017/18	68.5	66.5	78.9	72.9	75.9	60.4	69.0	71.1	59.7	67.6	61.6
Place of death - care home: People with dementia (aged 65 years and over)	2017/18	58.0	56.5	71.6	57.1	65.2	49.7	58.0	64.2	49.6	55.5	51.2
Place of death - hospital: People with dementia (aged 65 years and over)	2017/18	30.5	32.0	20.0	24.3	23.4	37.9	28.6	28.0	38.9	30.5	36.5
Place of death - home: People with dementia (aged 65 years and over)	2017/18	9.9	9.5	7.0	15.7	10.3	10.2	10.4	6.4	9.2	12.1	10.2

Why do we have the challenges?

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NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾, BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾, Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾, Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL

- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

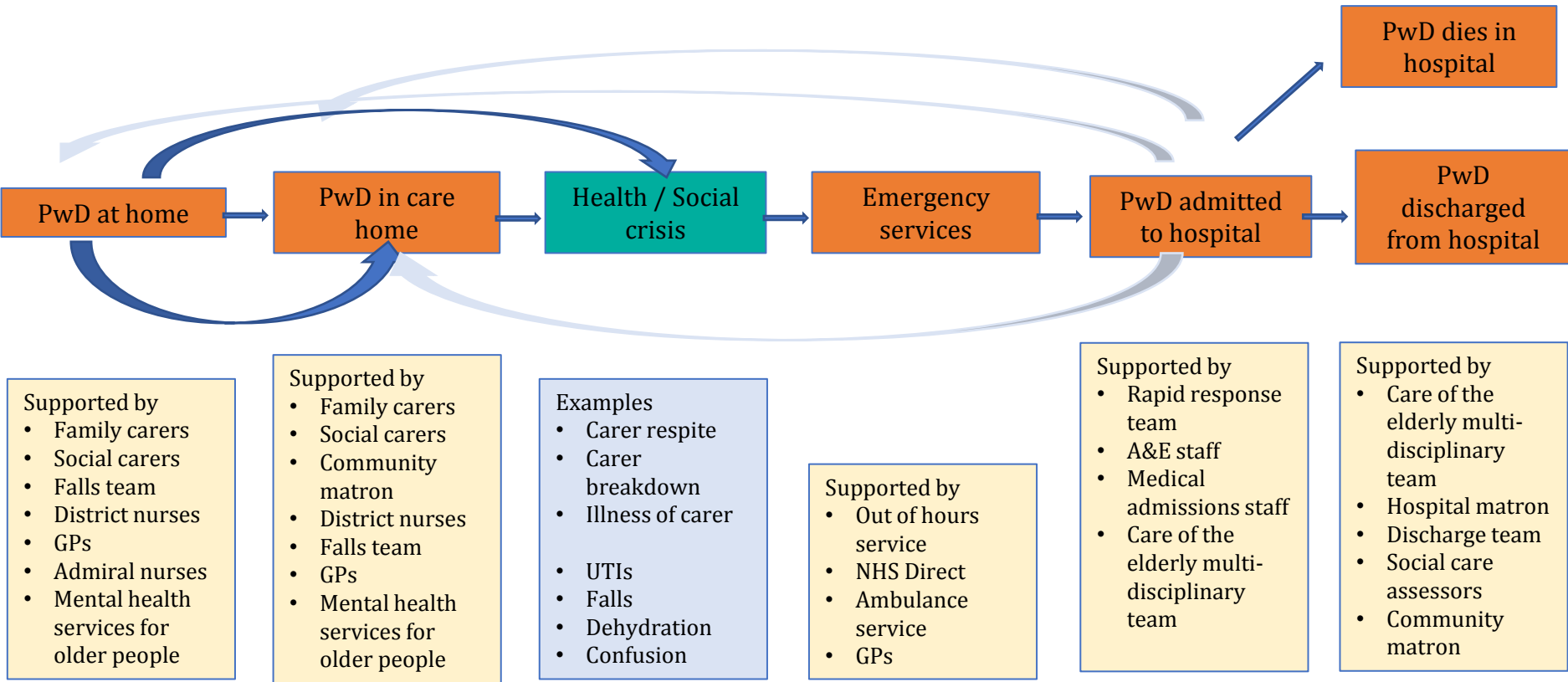
MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

Poor transitions of care

- **Transitional care** refers to the coordination and continuity of health **care** during a movement from one healthcare setting to either another or to home, called **care transition**, between health **care** practitioners and settings as their condition and **care** needs change during the course of a chronic or acute illness.

Typical life journey for People with Dementia (PwD) showing multiple transitions of care



Adapted from: <https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/past-initiatives/end-of-life-care-and-dementia/end-of-life-project-report.pdf>

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- Examples
- Carer respite
- Carer breakdown
- Illness of carer

- UTIs
- Falls
- Dehydration
- Confusion



Costs

Increased length of stay

Increased re-admission rates

Care Home Admissions

Mortality/Morbidity

Increased adverse events

Increased emotional and physical pain

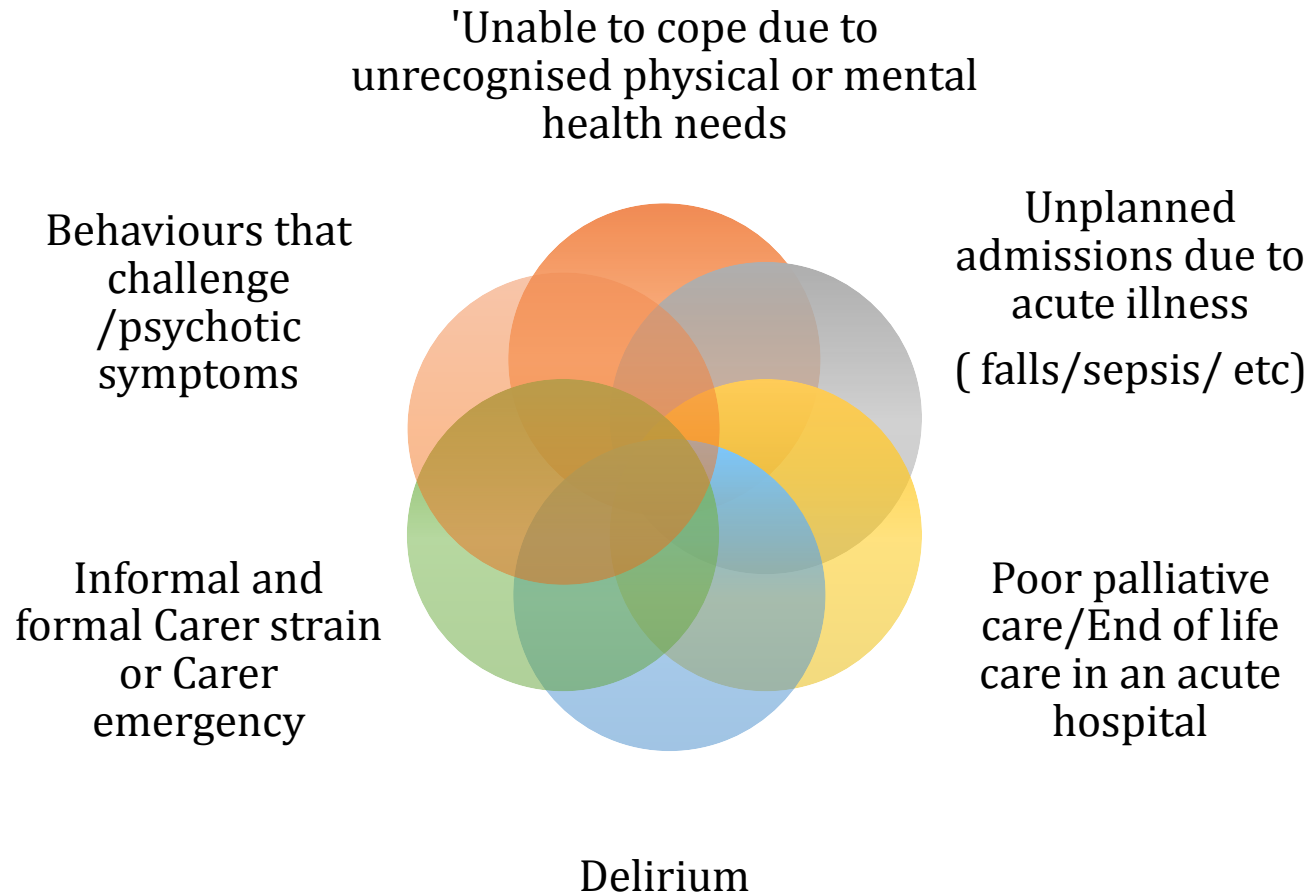
Relationship Breakdowns

Experience

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How might a crisis present?



Burdensome Transitions for People with Dementia near the End of Life

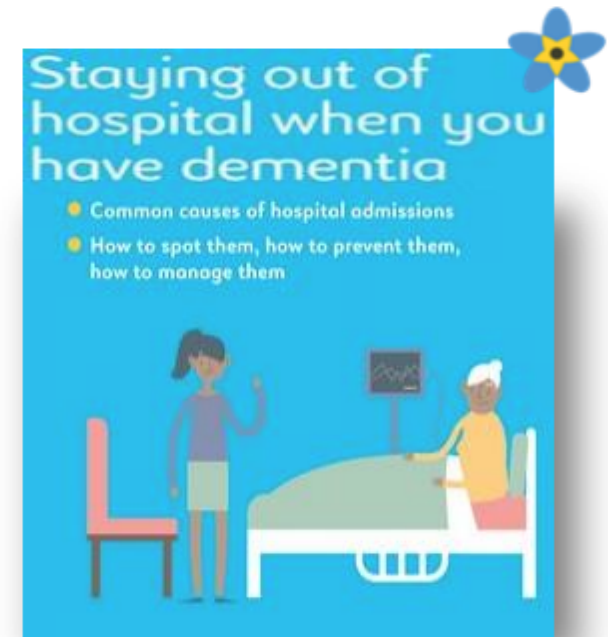
- Transitions between care settings at the end of life can result in adverse consequences, particularly for individuals with dementia.
- ‘Burdensome’ transitions have been defined as transitions in the last 3 days of life, or multiple transitions (≥ 2 from infection or ≥ 3 from any cause) in the last 90 days of life.
- Individuals with multiple transitions in the last 90 days were more likely to be male, have physical illness problems and problems with depressed mood and less likely to be living in a care home
- Burdensome Transitions for People with Dementia near the End of Life: Retrospective Cohort Study Using Linked Clinical and Administrative Data [Katherine Sleeman](#)KCL

What are we trying to do to reduce the challenges?

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- Working with 3 STPs to take part in project
- Bring together a range of measures with potential to reduce:
 - unnecessary admissions
 - length of stay
- Person centred meaningful care
- Targeting care homes and individual residents within those homes for bespoke support



Progressing the initiative

- Work on reducing Delirium in Hospitals/Care Homes and in a primary care setting
- Increased uptake of advance and emergency care planning
- An inpatient matrix to understand behaviours prior to discharge





Dementia Research

Coming back to research-Why is there not more Dementia Research in primary care?

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The Challenges for Primary Care?

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Challenges!

- Disempowerment
- Low Diagnosis rates
- Populations in 1'care v studies in 2'care
- Primary care lead by doctors v studies coming from schools of nursing/therapy etc
- Difficulty engaging Care Home
- Mental Capacity
- Lack of popularity
- Who gets the accruals!
- Exclusion of BAME populations

The Opportunities for Primary Care?

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Opportunities!

- The Dementia Well Pathway /national direction
- Rising diagnosis rates
- JDR
- Collaboration with Universities-PhD studies
- GP Champions
- GPwSI
- Collaborations between 1' and 2 'care
- Dementia Friendly Surgeries
- Annual care Planning reviews
- PPGs and Patient ambassadors



**To see if you can help a dementia research
study visit:**

www.joindementiaresearch.nihr.ac.uk

Or call our one of our helplines:



Alzheimer's Research UK (0300 111 5 111)
Alzheimer's Society (0300 222 1122)

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Finally why does research not lead to better care?

Some Gaps!

- Lack of collaboration between the ‘Dementia real World’ and the ‘Research World’
- A Gap between how topics for studies are developed and the actual needs of front line staff
- A Gap in the commissioning of research into some strands of the Dementia Well Pathway
- Not using the the research published to commission care .
- A mismatch in moving small scale research to real world settings.

How do we change this?

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COMMISSIONERS

CLINICAL NETWORKS



PLWD



Universities



CRN

NIHR



CCG

GPs

Acute and Mental Health Providers



Conclusions?

Dementia is a growing issue for society but Dementia awareness and care is improving and Dementia research is on the way up-so we just need to now ensure we collaborate to ensure that the best evidence leads to better care

Thank You!

- sara.humphrey@bradford.nhs.uk