

Changes in Dementia Incidence, Prevalence, Severity and Mortality

Estimating future demand across the Dementia pathway

A support pack for commissioning Dementia services

NHS Dudley Clinical Commissioning Group



Midlands and Lancashire
Commissioning Support Unit

Key points for the CCG

There has been a sustained increase in Dementia prevalence in recent years, likely due in part to improved ascertainment.

There are significant practice variation in reported prevalence even accounting for age profiles.

There are estimated to be around **4,067** patients in the CCG with Dementia.

Currently **58.6%** are on Dementia disease registers, compared to **58.0%** regionally.

Projections for the CCG suggest there may be around **4,891** patients living with Dementia by 2021.

In order for the CCG to achieve the 67% diagnosis aspiration, they require **1,368** new diagnosis throughout 2015.

If not already, the CCG should consider implementing or improving the following interventions along the Dementia pathway:

- Primary prevention – CVD risk-reduction
- More timely and accurate diagnosis
- Integrated care:
 - Social Care
 - MDT across 1^o and 2^o care
 - Training for housing and nursing home staff
- Ongoing palliative care
- Carer support
- Dementia friendly communities and hospitals

Background

There are currently estimated to be over $\frac{3}{4}$ million people in the UK living with Dementia, costing society over £26 billion per year. Returns from primary care disease registers and national prevalence estimates suggest a large diagnosis gap across the UK [1].

These numbers and costs are likely to rise materially over the coming years in line with demographic changes to the population [2].

Primary and secondary mental health services will require detailed information to support service planning.

HSCIC and NHS England have made information available on the underlying prevalence of dementia and the number of dementia cases known to primary care.

Whilst this information is useful, effective service planning will require detailed information about for example, the number of new cases of dementia, the progression of patients between mild, moderate and advanced stages and the number of dementia patients who are expected to die each year.

This support pack is intended to help understand the need for future dementia diagnosis and treatment services in their area and to identify and prioritise interventions.

[1] Dementia Prevalence Calculator, Primary Care Webtool, NHS England

[2] Dementia UK: Second edition, Alzheimer's Society, September 2014

Pack contents

There are 4 principle components to the analysis presented in this report:

1. A review of historic and current rates of formal diagnosis of Dementia from Primary Care registers
2. Estimates of the likely prevalence using the latest literature - thus deriving diagnosis rates.
3. Estimates of the future incidence, severity of disease and mortality using the latest population projections and a Markov chain modelling approach
4. Estimates of the prevalence of dementia in nursing and care homes.

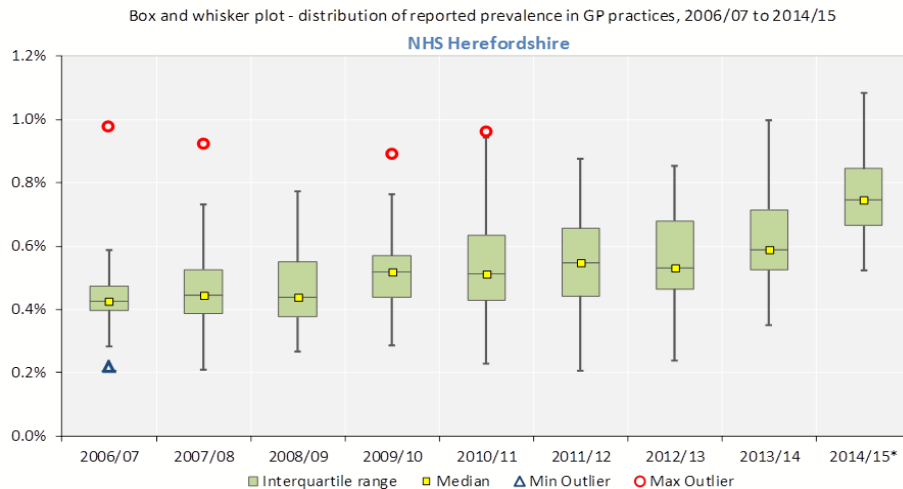
Steps 1 & 2 replicate information that is already available via the HSCIC and NHS England's Dementia Prevalence Calculator, however they are necessary steps in developing the model (step 3) that predicts the future burden of Dementia.

Whilst the modelled estimates in 3 & 4 are presented here unadjusted in the report, it should be noted that due to the margin for error, figures rounded to the nearest 50 or 100 should be used for planning assumptions.

NB. Due to slight methodological differences or variations in assumptions, the outputs of our modelling are comparable but may not match precisely with that of existing modelled estimates of dementia prevalence from other sources.

How to interpret the information

Box and Whisker plots:

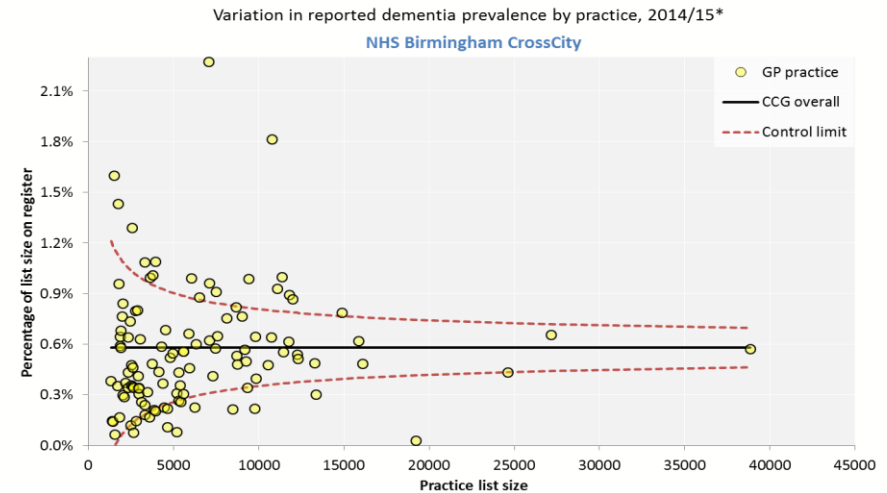


These charts show the distribution of practice data in the CCG for each year of QOF. The green bars show the interquartile range (IQR, the middle 50% of practices) and the yellow circle on line shows the median (middle) value of all practices.

If the IQR is small, then the practices tend to have similar prevalence. A larger IQR suggests a greater variation in prevalence. If the median is not in the centre of the IQR then the data are skewed i.e. more practices are above/below the average.

Maximum and minimum outliers are also shown so the full extent of the data range can be seen.

SPC Funnel charts:



The funnel charts show the spread of reported prevalence data by practice in the context of the practice list size. Practices with smaller populations have a wider range of values that would be considered 'normal'. The red lines in funnel shape represent control limits (equivalent to 3 standard deviations from the CCG mean). Practices falling outside these limits demonstrate 'special cause variation' and may be worthy of further investigation.

The reasons for high outliers may be that they are nursing home practices therefore have a particularly high prevalence. Similarly, those practices with very low prevalence may be University practices and thus have few patients with Dementia.

However, any outlying practice may also have good or poor processes in place to identify new Dementia patients.

1. Evaluation of changes over time and variation in reported Dementia prevalence

The following information utilises publically available QOF data at practice and CCG level.

Changes to diagnosed prevalence over time for practices and CCGs are compared to national and regional trends and assessed for significance of any differences.

The nature and extent of current variation in practice and CCG-level prevalence is evaluated using statistical process control methods to identify potential outliers.

Projections are provided for future disease register sizes to 2021 **on the basis of 67% (2015) and 80% (2021) ascertainment rates.**

For pre-CCG information, data is processed at practice level and aggregated to current CCG configurations. Where historic practices do not exist in current CCG configurations, they are allocated on a PCT-to-CCG best fit basis. Although small in number, this may affect some CCG outputs more than others.

1. Evaluation of changes over time and variation in reported Dementia prevalence

Trends in diagnosed prevalence, 06/07 to 14/15*

Reported prevalence trajectory (QOF) in CCG, Region and England (relative growth 06/07 to 14/15 in brackets): **NHS Dudley**

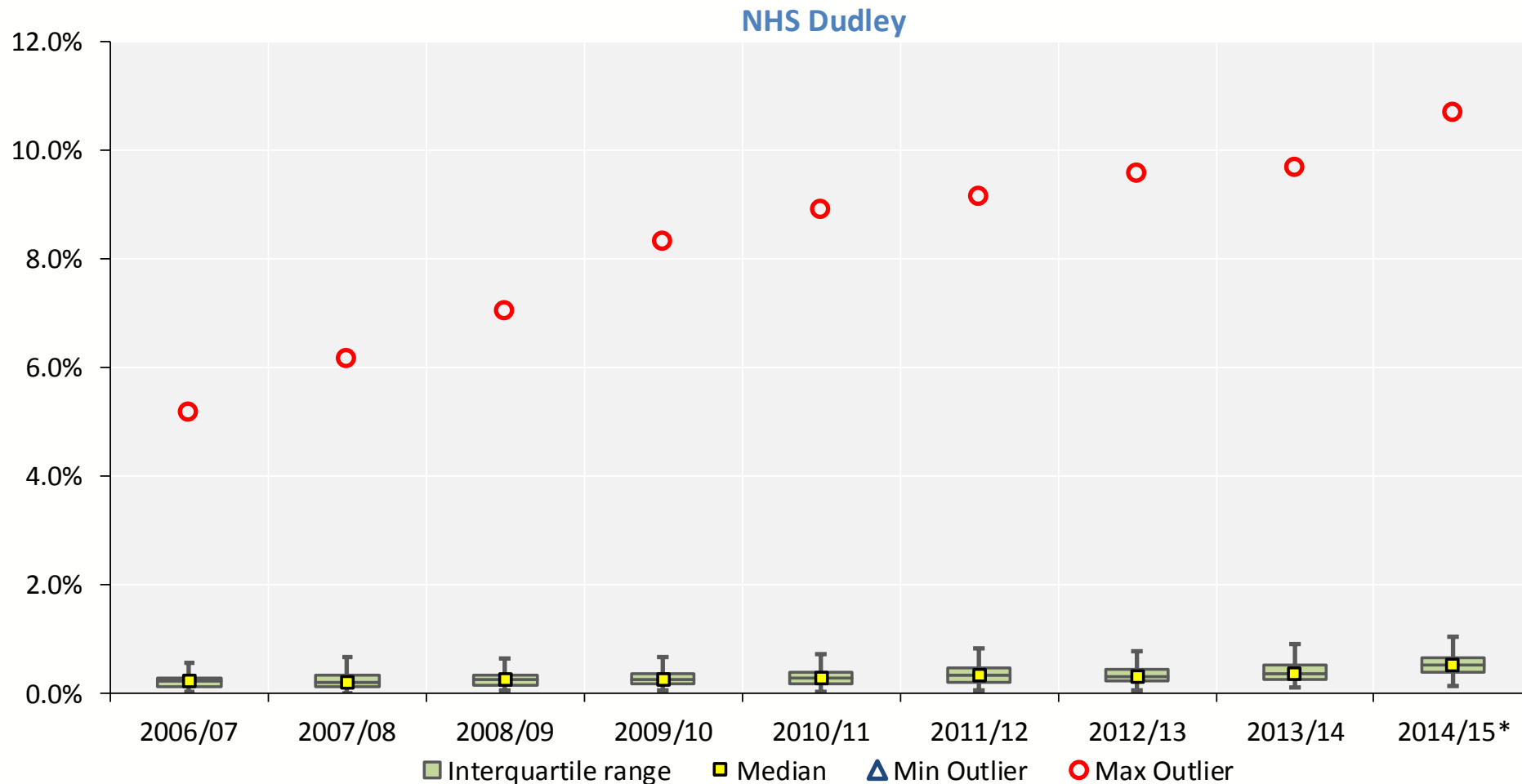


* Prevalence figures for 2014/15 are based on the Dementia-specific QOF returns as at March 2015 published by the HSCIC. Final QOF prevalence figures for 14/15, when published, may differ slightly.

1. Evaluation of changes over time and variation in reported Dementia prevalence

Variation in current reported prevalence [1]

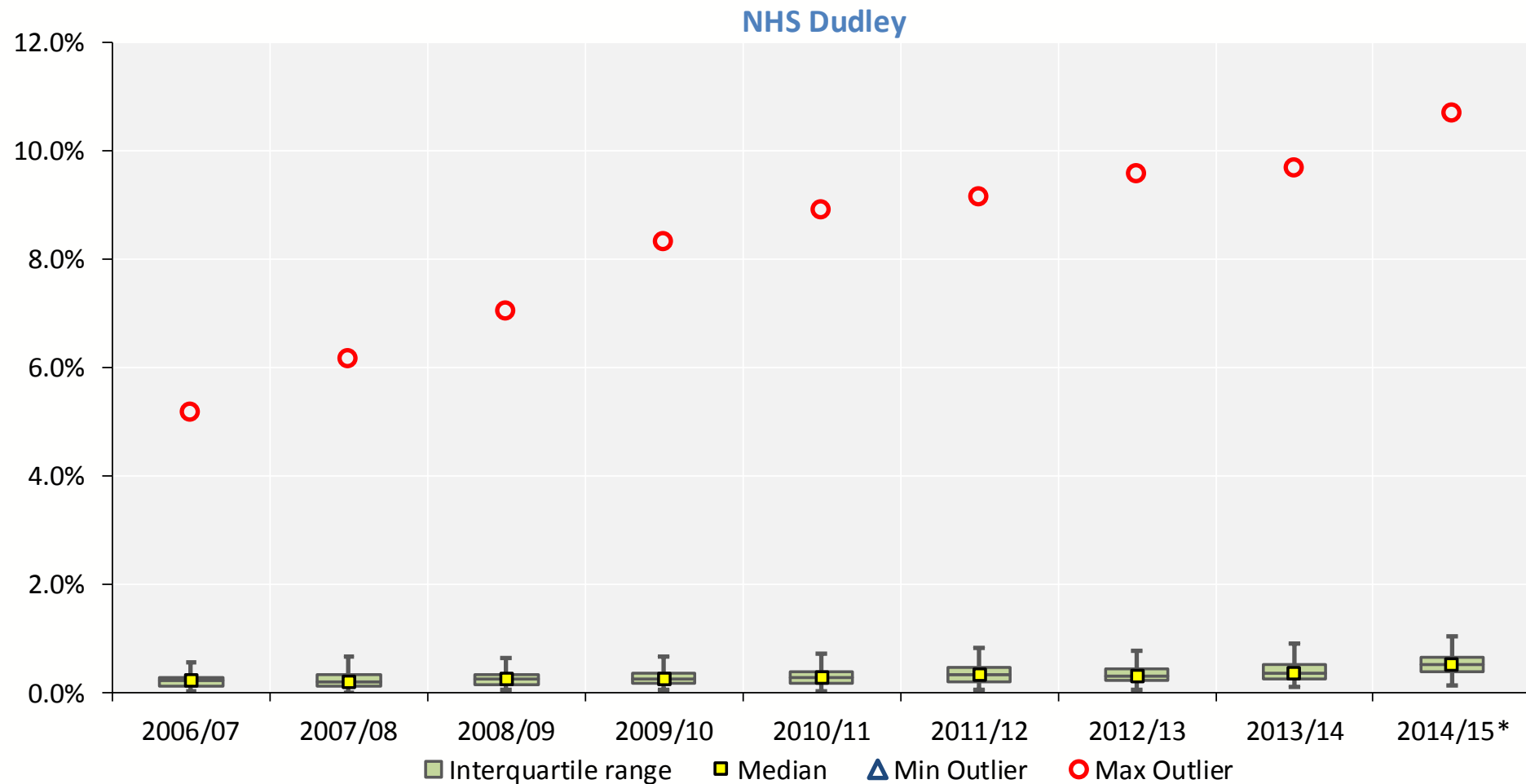
Box and whisker plot - distribution of reported prevalence in GP practices, 2006/07 to 2014/15



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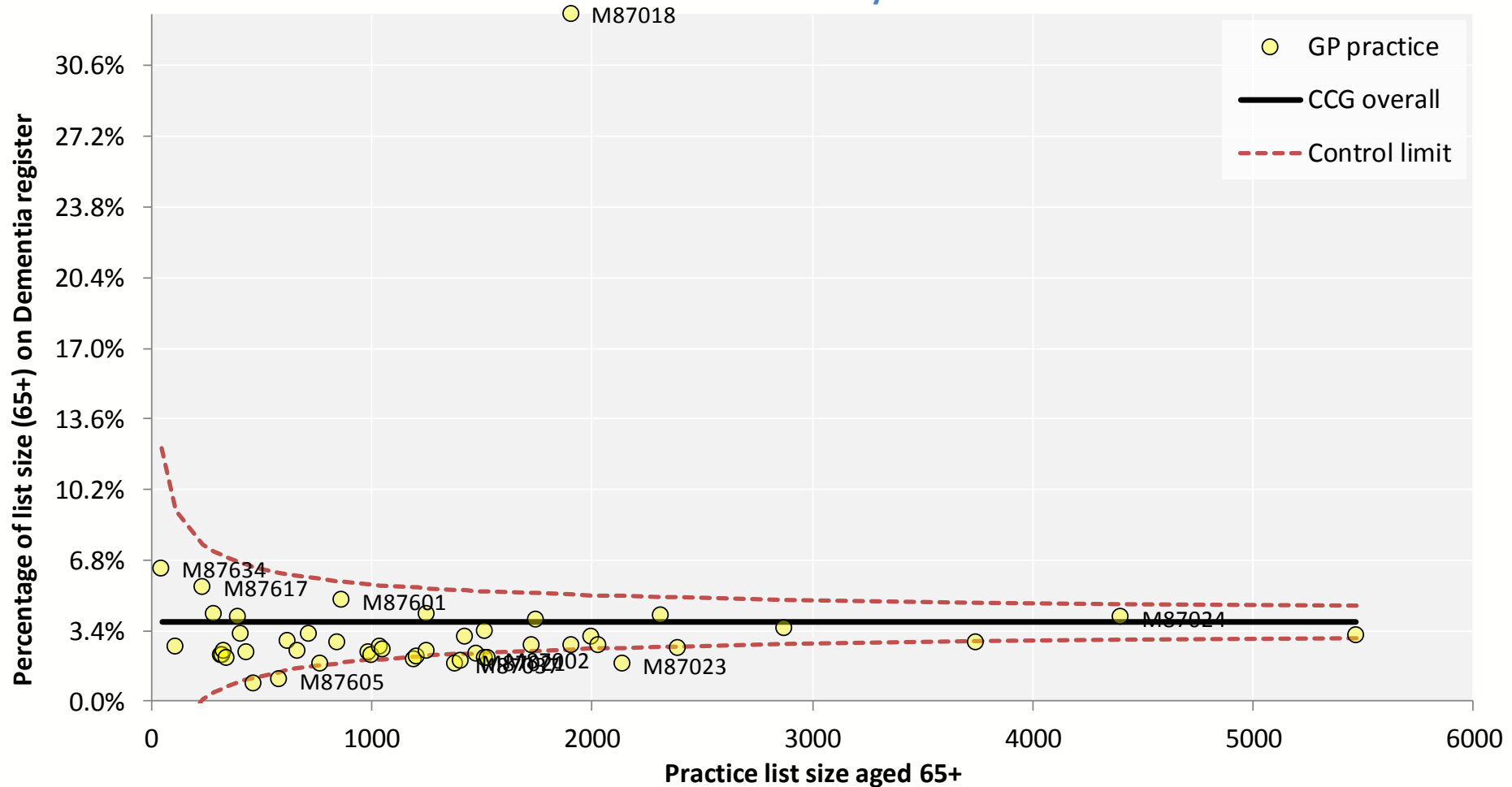


1. Evaluation of changes over time and variation in reported Dementia prevalence

Variation in current reported prevalence [2]

Variation in reported dementia prevalence in 65+ population by practice, 2014/15

NHS Dudley



1. Evaluation of changes over time and variation in reported Dementia prevalence

Variation in current reported prevalence [3]

Practices with the highest number of cases relative to 65+ list size 2014/15:

Code	Practice Name	Patients 65+	with Dementia
M87018	SUMMERHILL SURGERY	1,904	630
M87601	KEELINGE HOUSE SURGERY	864	42
M87617	NETHERTON SURGERY	235	13
M87634	ST. THOMAS'S MEDICAL CENTRE	47	3
M87024	WYCHBURY MEDICAL GROUP	4,399	178

The reasons for high outliers may be that the practice has a high volume of nursing home patients therefore has an artificially high prevalence. These practices may also have good early diagnosis processes in place.

Practices with the lowest number of cases relative to 65+ list size 2014/15:

Code	Practice Name	Patients 65+	with Dementia
M87023	WORDSLEY GREEN HEALTH CENTRE	2,136	38
M87037	THE NORTHWAY SURGERY	1,376	25
M87021	COSELEY MEDICAL CENTRE	1,404	27
M87002	NORTON MEDICAL PRACTICE	1,513	31
M87605	CENTRAL CLINIC	580	6

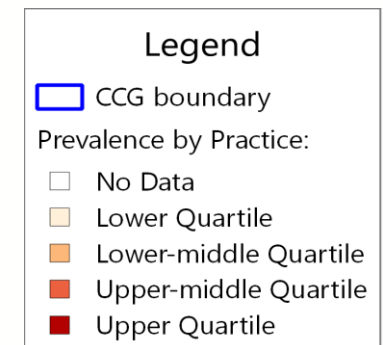
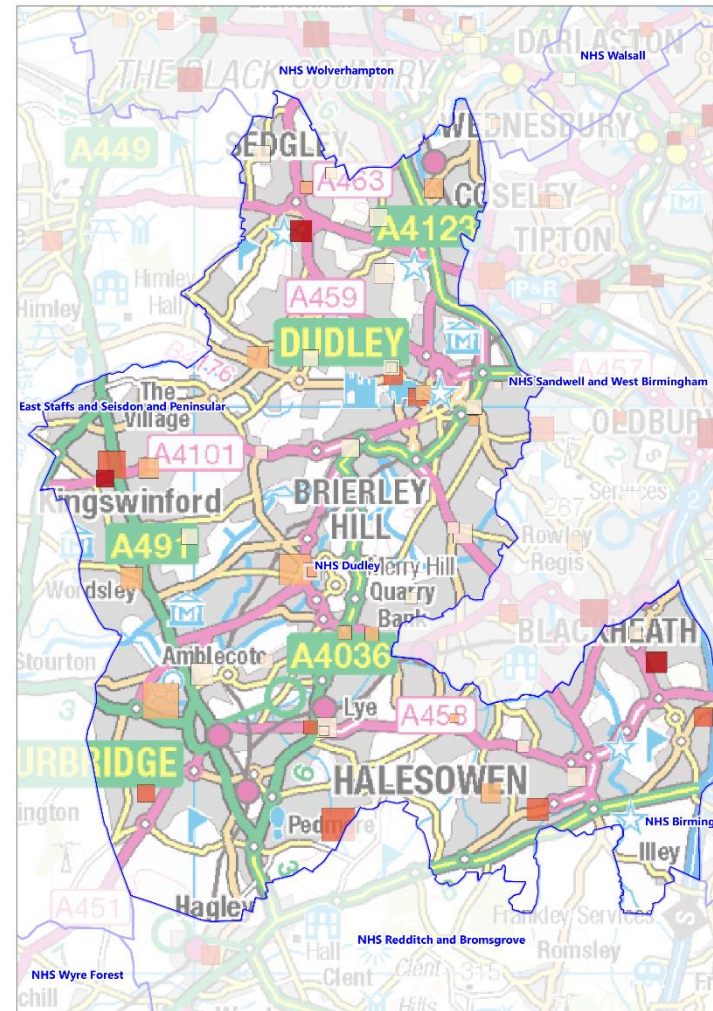
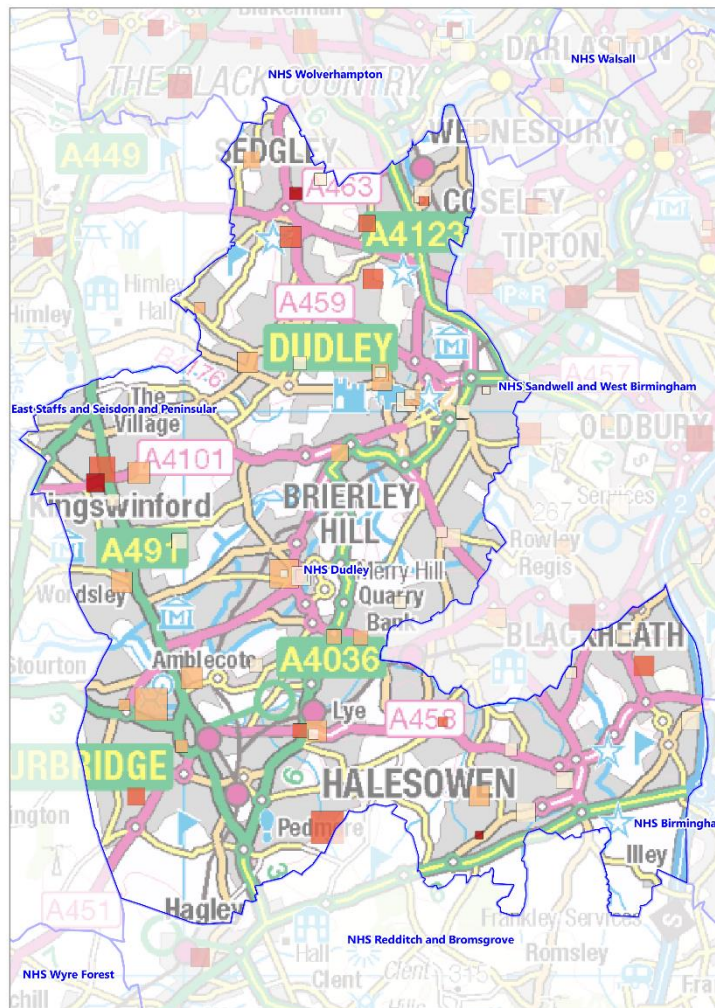
Practices with very low prevalence may be University practices and thus have few patients with Dementia. Alternatively they may have poor processes in place to assess and refer potential Dementia patients.

1. Evaluation of changes over time and variation in reported Dementia prevalence

Geographical variation in reported prevalence

2006/07

2013/14



NB. Size of practice 'squares' is in relation to the median list size across the 2 periods. As such, any changes in size reflects an increase/decrease in list size to 2013/14.

2. Estimating the total number of Dementia patients

This analysis utilises the latest prevalence estimates [3,4] to model the likely true prevalence of Dementia. As these estimates combine pre-65 and 65+ age-specific prevalence from different sources, they may differ slightly from those published in the Dementia Prevalence Calculator.

Rates have been applied to Clinical Commissioning Groups using the most up-to-date age and gender resident population counts from ONS adjusted for registration to resident ratios [5].

A break-down of dementia diagnosis by severity/stage and by Dementia sub-type for the CCGs is presented.

For the purposes of this report, the definition of Dementia stages has been taken from Dementia UK report, 2007 [6].

The modelled prevalence for 2014 is compared to the year-to-date reported prevalence in 2014/15 to derive a 'diagnosis rate'. The variation in this measure is assessed across the region at CCG level and by using statistical process control charts [7] to determine significant variance from the national average.

[3] CFAS II. Matthews, Fiona E et al. The Lancet , Volume 382 , Issue 9902 , 1405 – 1412

[4] Dementia UK: Second edition, Alzheimer's Society, September 2014

[5] Office for National Statistics, mid-year population estimates 2013.

[6] Knapp M, Prince M. Dementia UK. Alzheimer's Society, 2007.

[7] Flowers J. Technical briefing 2: Statistical process control methods in public health intelligence. APHO, December 2007.

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2. Estimating the total number of Dementia patients

Overall burden of disease [1]

The current total estimated number of patients in the CCG with Dementia is

4,067

This is projected to rise to **4,891** -

a net increase of **824** by the year 2021.

Dementia sub-type, 2014	Estimate	%
Alzheimer's disease	2,521	62%
Vascular dementia	691	17%
Mixed dementia	407	10%
Dementia with Lewy bodies	163	4%
Frontotemporal dementia	81	2%
Parkinson's dementia	81	2%
Other	122	3%
Total	4,067	

Year	Mild	Moderate	Advanced
2014	2,325	1,297	445
2021	2,768	1,565	558
Change	443	268	113
% change	19.1	20.6	25.5

In the latest available QOF data (2014/15 to Mar 31st) for disease registers **2,385** patients are being managed by GPs in the CCG for Dementia – a diagnosis rate of **58.6%** compared to **58.0%** across the region as a whole.

2. Estimating the total number of Dementia patients

Overall burden of disease [2]

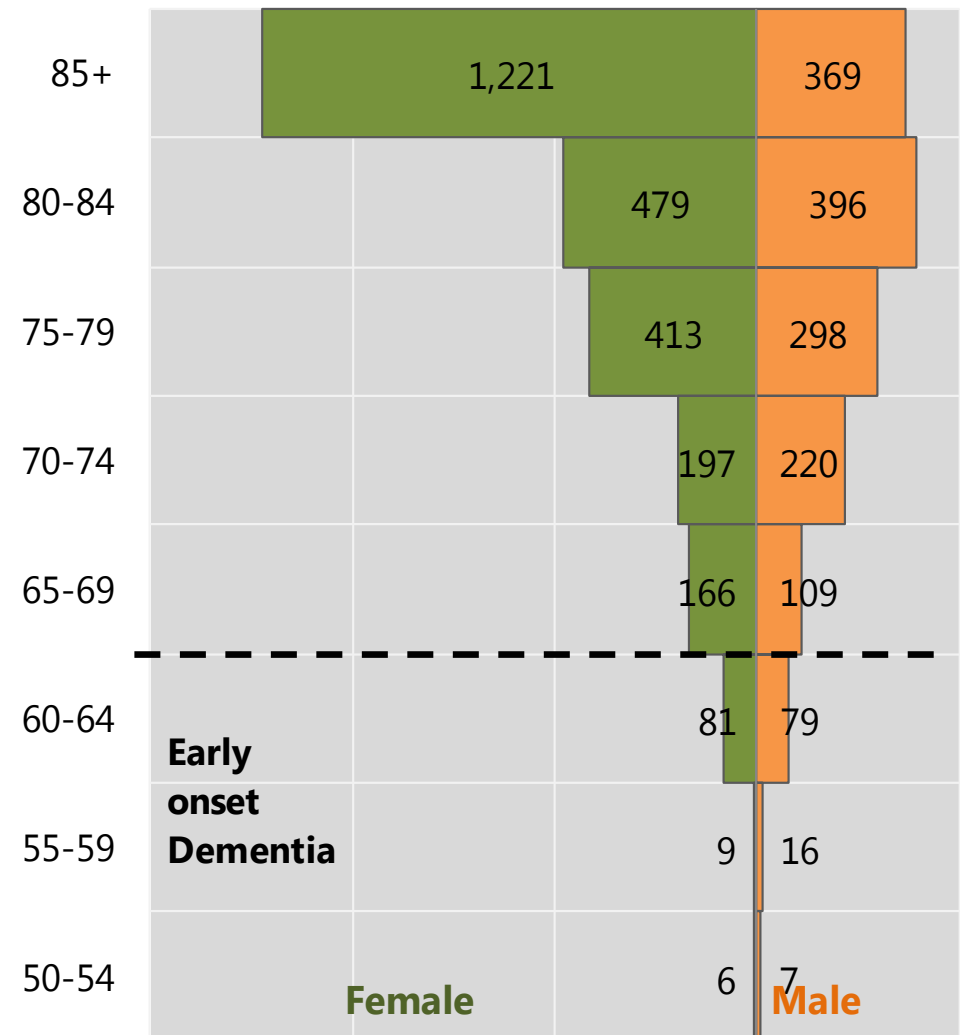
Estimated number of people with Dementia by age and gender, 2014 and 2021

Age-group	2014		2021	
	Male	Female	Male	Female
50-54	7	6	7	6
55-59	16	9	19	11
60-64	79	81	82	83
65-69	109	166	98	154
70-74	220	197	249	220
75-79	298	413	354	470
80-84	396	479	494	533
85+	369	1,221	561	1,549
Aged 50+	1,494	2,573	1,864	3,027

The numbers of early-onset dementia cases in the CCG population are relatively small compared to the overall burden and unlikely to increase dramatically over the next few years.

'Population' pyramid for Dementia, 2014

NHS Dudley



2. Estimating the total number of Dementia patients

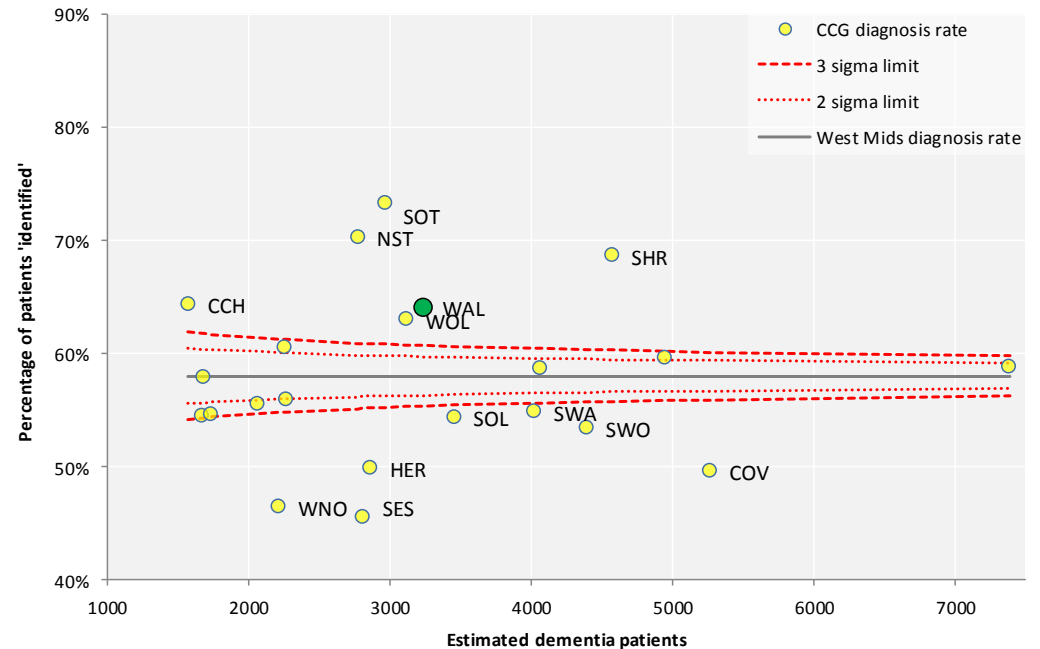
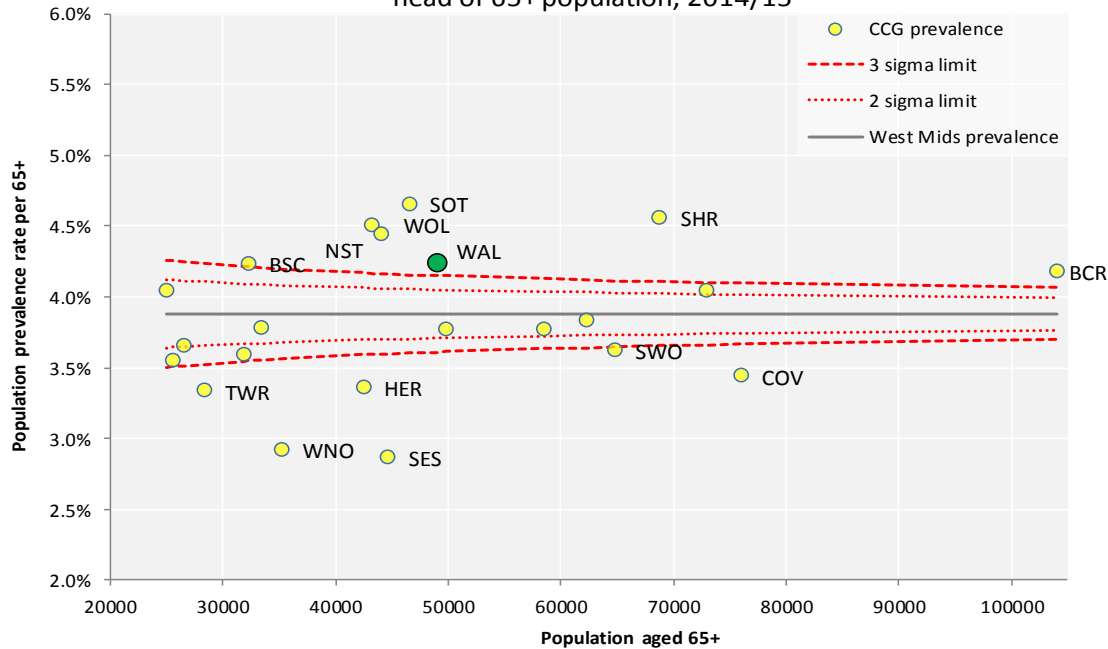
Variation in prevalence and diagnosis rates

Reported prevalence

Diagnosis rate

Variation in reported prevalence of Dementia by West Midlands CCG, per head of 65+ population, 2014/15

Diagnosis ratio of Dementia patients by West Midlands CCG, 2014/15



The CCG currently has well above average reported prevalence **and** current diagnosis rates compared to the region as a whole.

This may suggest overall the systems in place for the identification of disease are GOOD compared to the West Midlands, although improvements can always be made in diagnosis across disease stages, for all age groups and in some GP practices.

3. Predicting the future number of Dementia patients across the pathway.

Analysis at this level utilises the latest evidence of disease progression and mortality in dementia at a population level [10]. We have assumed a static age-specific incidence rate over time in the absence of quality evidence to the contrary.

The model parameters haven been applied to the latest CCG-specific population projections [11]. These projections are based on resident populations within CCG geographical boundaries.

As such, prior to modelling we have adjusted the total resident population by historic CCG registered-to-resident population ratios and applied the resident-based age and gender population distribution to obtain estimates for CCG-registered populations.

A Markov chain model approach is used to allocate numbers of patients to different states of disease over time, forecasting these likely states up to 2021. These are compared to aspirational diagnosis rates to 2015 and 2021 of 67% and 80% respectively to identify opportunities for the identification of new cases of dementia.

[10] Launer LJ et al. Rates and Risk factors for Dementia and Alzheimer's disease. EURODEM Incidence Research Group, 1999

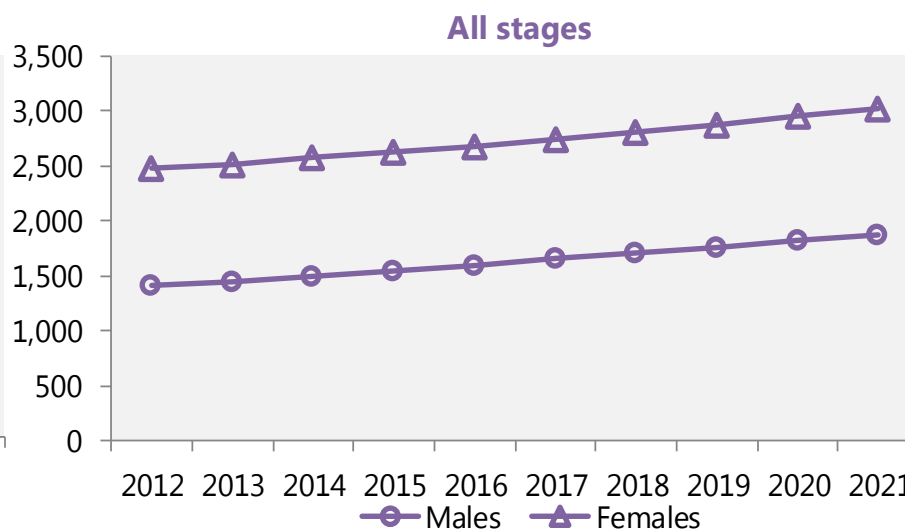
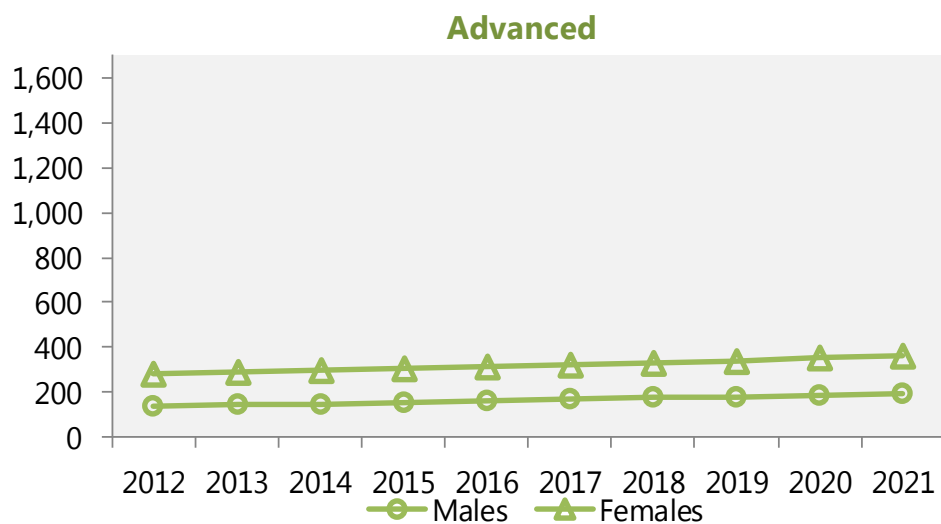
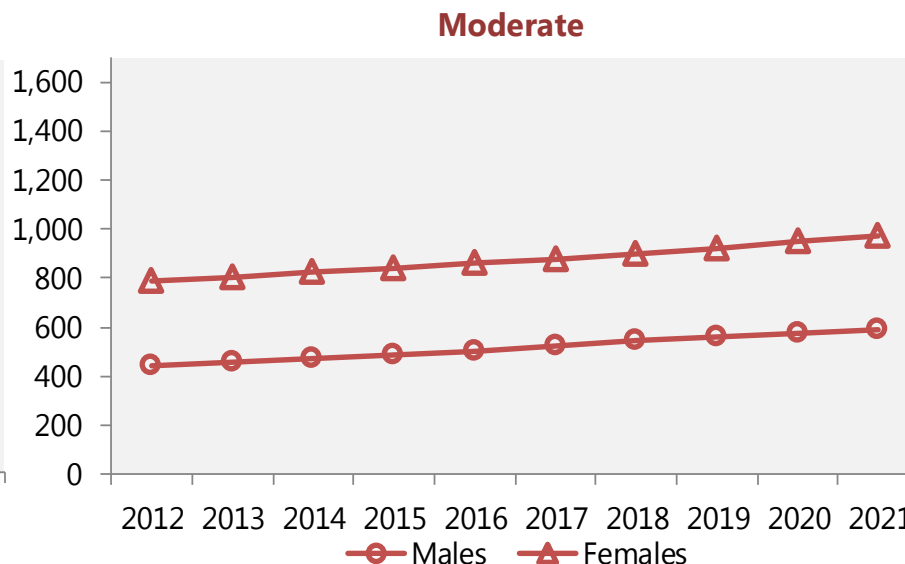
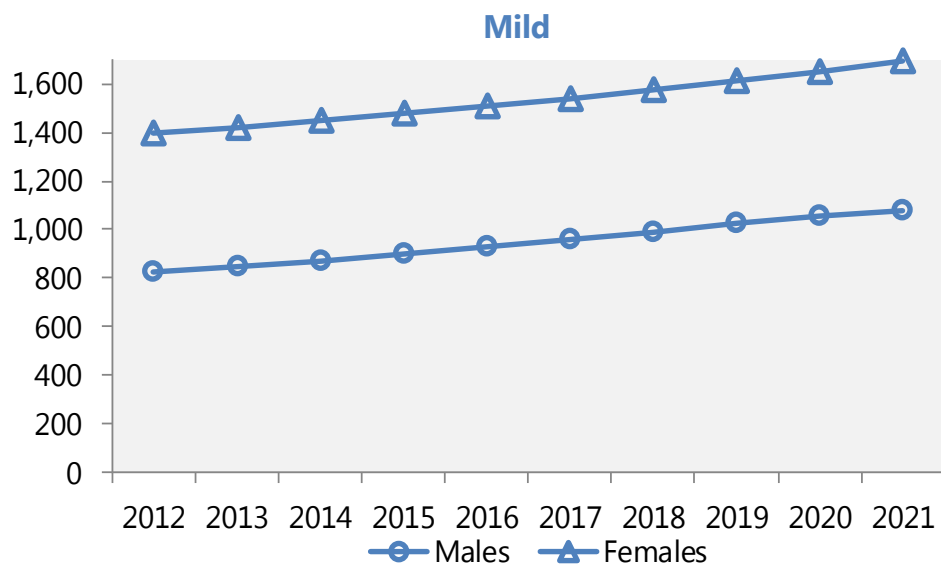
[11] Mid-year population estimates and 2013-based SNPP. Office for National Statistics

3. Predicting the future number of Dementia patients across the pathway.

Overall burden of disease [1]

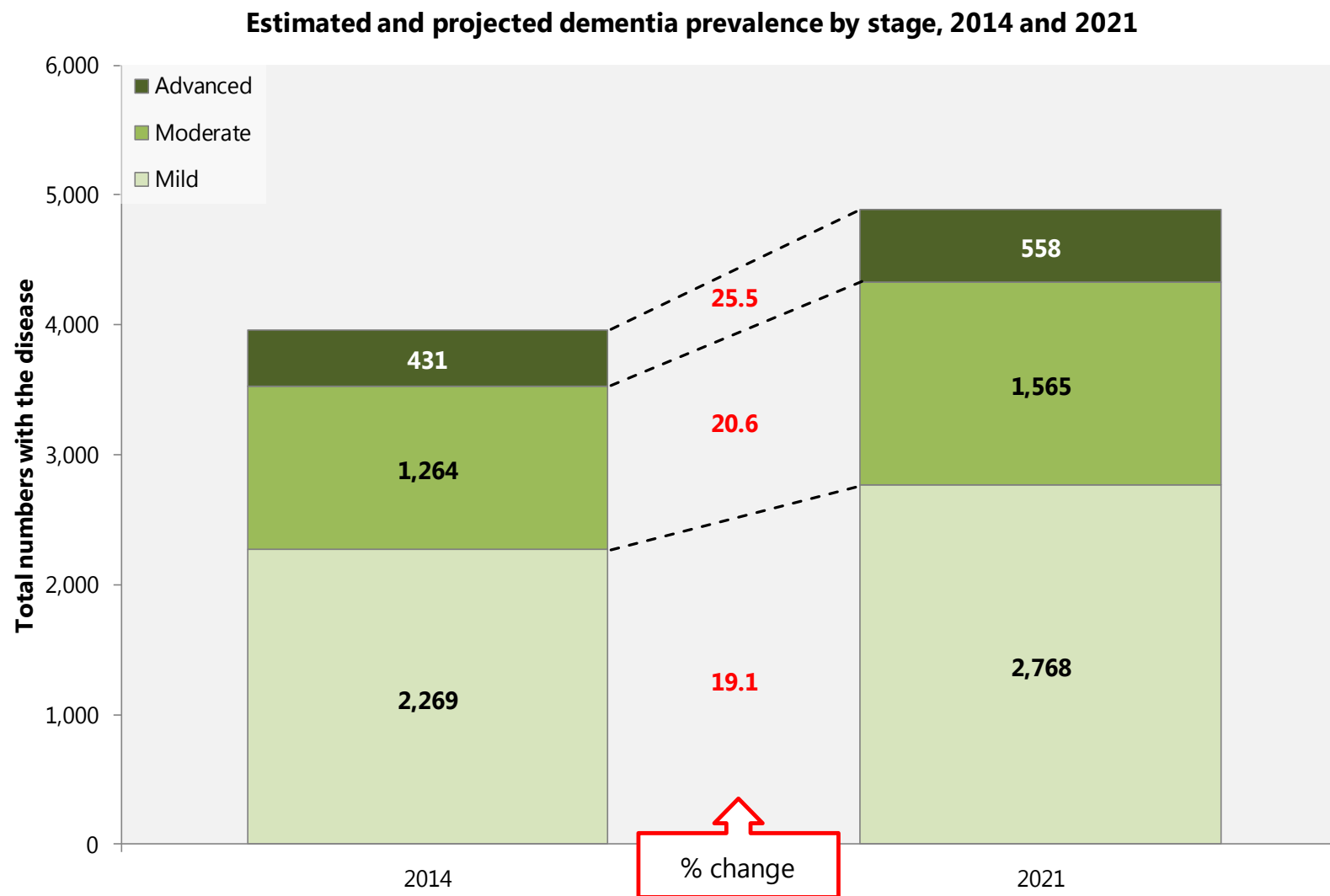
Estimated number of prevalent cases of Dementia by stage and gender, 2012 to 2021

NHS Dudley



3. Predicting the future number of Dementia patients across the pathway.

Prevalence by disease stage

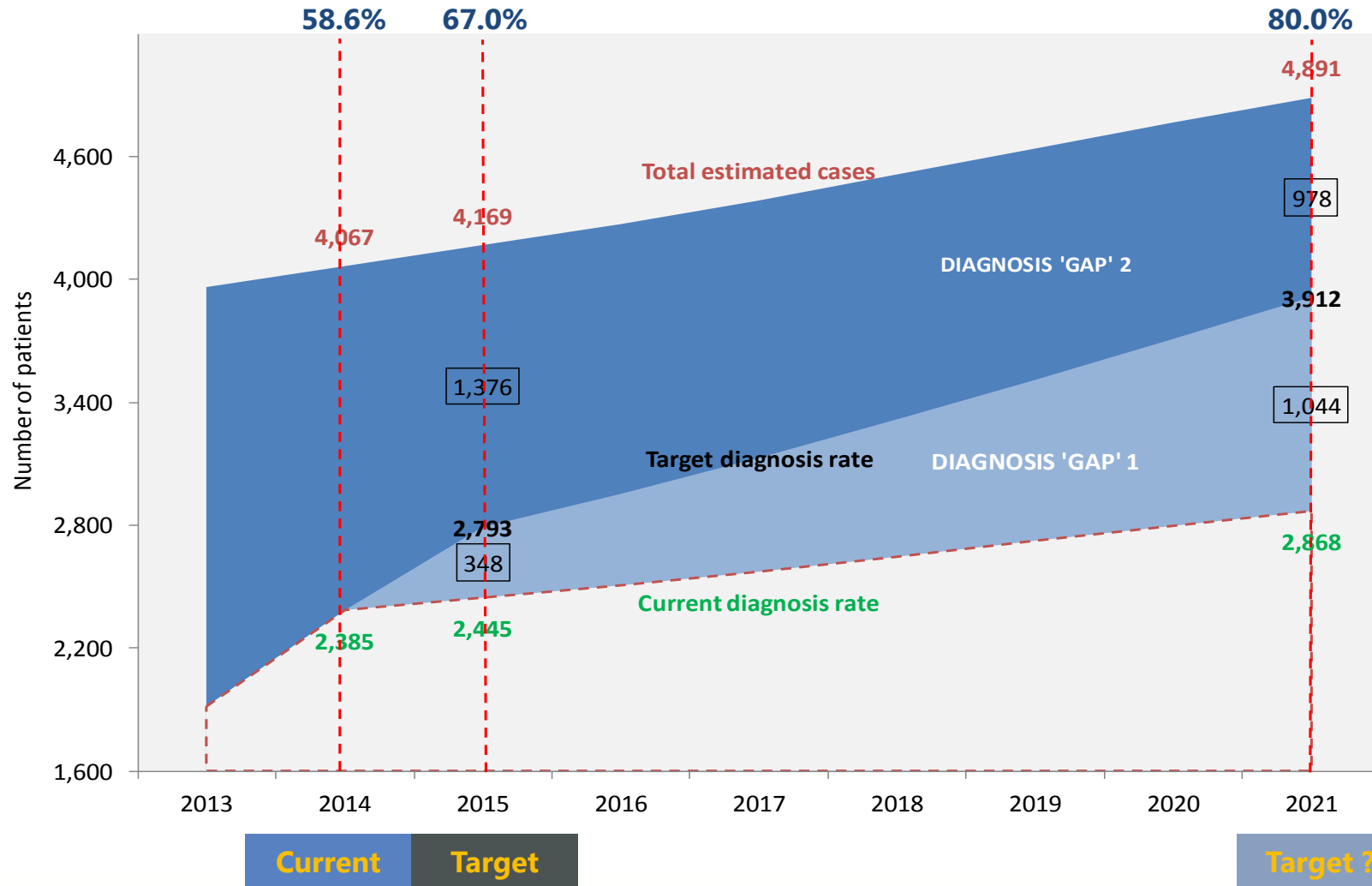


3. Predicting the future number of Dementia patients across the pathway.

Aspiration and opportunity for diagnosis

Opportunity for case-finding - the gap between estimated and diagnosed patients:

NHS Dudley



'Diagnosis gap 1' refers to the difference between diagnosed numbers at the current rate (Jan '15) and the aspirational rate for the CCG.

'Diagnosis gap 2' is the difference between 100% ascertainment of estimated cases and the aspirational rate for the CCG

3. Predicting the future number of Dementia patients across the pathway.

Diagnosis requirements for the CCG

Year	No. on Register (current rate)	Aspirational no. on register	Deaths from register prior year	New diagnosis requirement	New diagnosis required pppy ^{^*}
2013~	1,914	1,914	455	652	14
2014~	2,385	2,385	450	921	19
2015	2,445	2,793	459	867	18
2016	2,506	2,955	476	638	13
2017	2,574	3,131	485	660	14
2018	2,648	3,319	499	687	14
2019	2,723	3,513	517	711	15
2020	2,797	3,711	531	729	15
2021	2,868	3,912	554	755	16

[^] pppy = per practice per year

* assuming diagnosis gap met in prior year

~ actual numbers on register as per QOF

The 'opportunity' for diagnosis presented here is based on numbers of aspirational cases at year end (point prevalence). The sum of the change from the previous years' point prevalence (at aspirational rate) plus deaths during the prior year equate to the 'opportunity'.

As such, the number of newly identified patients required in any given period to even maintain the diagnosis rate exceeds that of the simple gap between the current and previous diagnosis aspirations.

The figures for each year depend on the previous year's diagnosis aspiration being met. Should they not, the volumes will accumulate and the gap become more challenging to close.

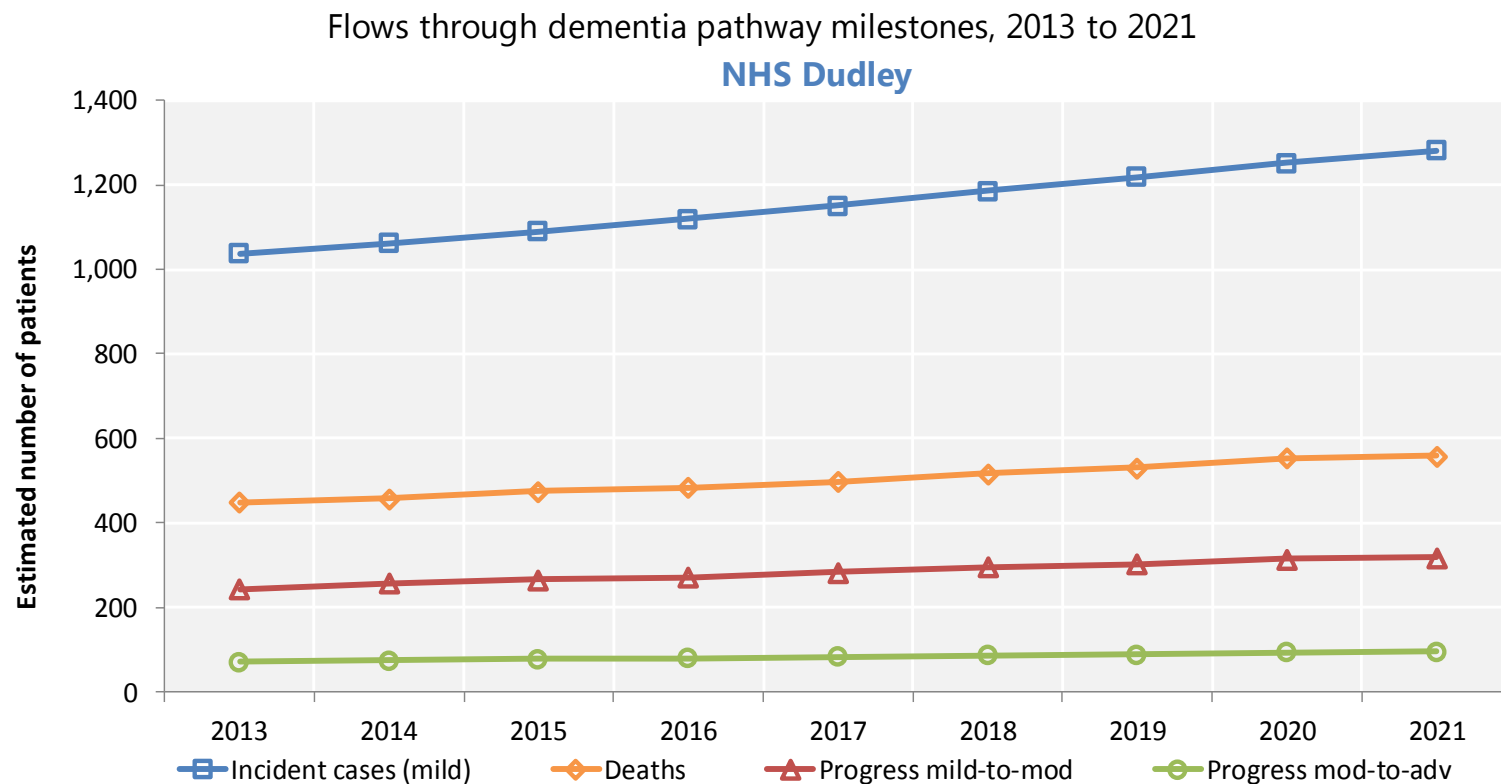
3. Predicting the future number of Dementia patients across the pathway.

Estimated patient flows for the CCG

The numbers of incident cases are rising steadily due to demographic changes, however the rate remains constant.

The number of deaths are estimated to rise at a slightly slower rate, hence the incremental growth in prevalence each year.

Across the CCG between 390 and 480 patients will progress from mild to moderate disease each year, and a further 130 to 160 from moderate to advanced stage disease.



The scale and nature of services for patients and their carers along each element of this pathway will vary by CCG. Where numbers are fairly small, neighbouring CCGs may wish to co-commission some services.

4. Estimates of Dementia in care and nursing homes.

Methods and summary

The exact number of persons living in care homes is not known. There has been no national data collection for GP populations since September 2011, for which an overall 'Nursing Home' population was counted [8].

The Census tells us how many people within a specified residential area live in care homes by type (Local Authority / Other with nursing / Other without nursing).

By applying these proportions to the latest CCG registered populations we can estimate the likely numbers in homes by type and thus derive further estimates of the numbers in the CCG with Dementia.

The prevalence estimates used here are the setting-based consensus estimates taken from the 2014 Dementia UK update report [9].

2021 estimates are based on the changes to the combined population prevalence of moderate and severe disease predicted by our model to that time. Overall numbers in nursing homes are assumed to remain constant.

	All*	With dementia*	
		2014	2021
CCG Patients in residential care (all)	2,025	1,280	1,518
Patients in Local Authority care homes	99	57	57
Patients in other care homes w/o nursing	1,214	703	840
Patients in other care homes with nursing	712	520	621

* Summed figures may differ to overall figures due to rounding

NB. These are broad estimates only, intended for high-level planning use. Specific and up-to-date local data collections would be required at GP or care home level when considering the design and scale of care home services and/or interventions.

[8] Health and Social Care Information Centre, Indicator Portal, Data item number P01109

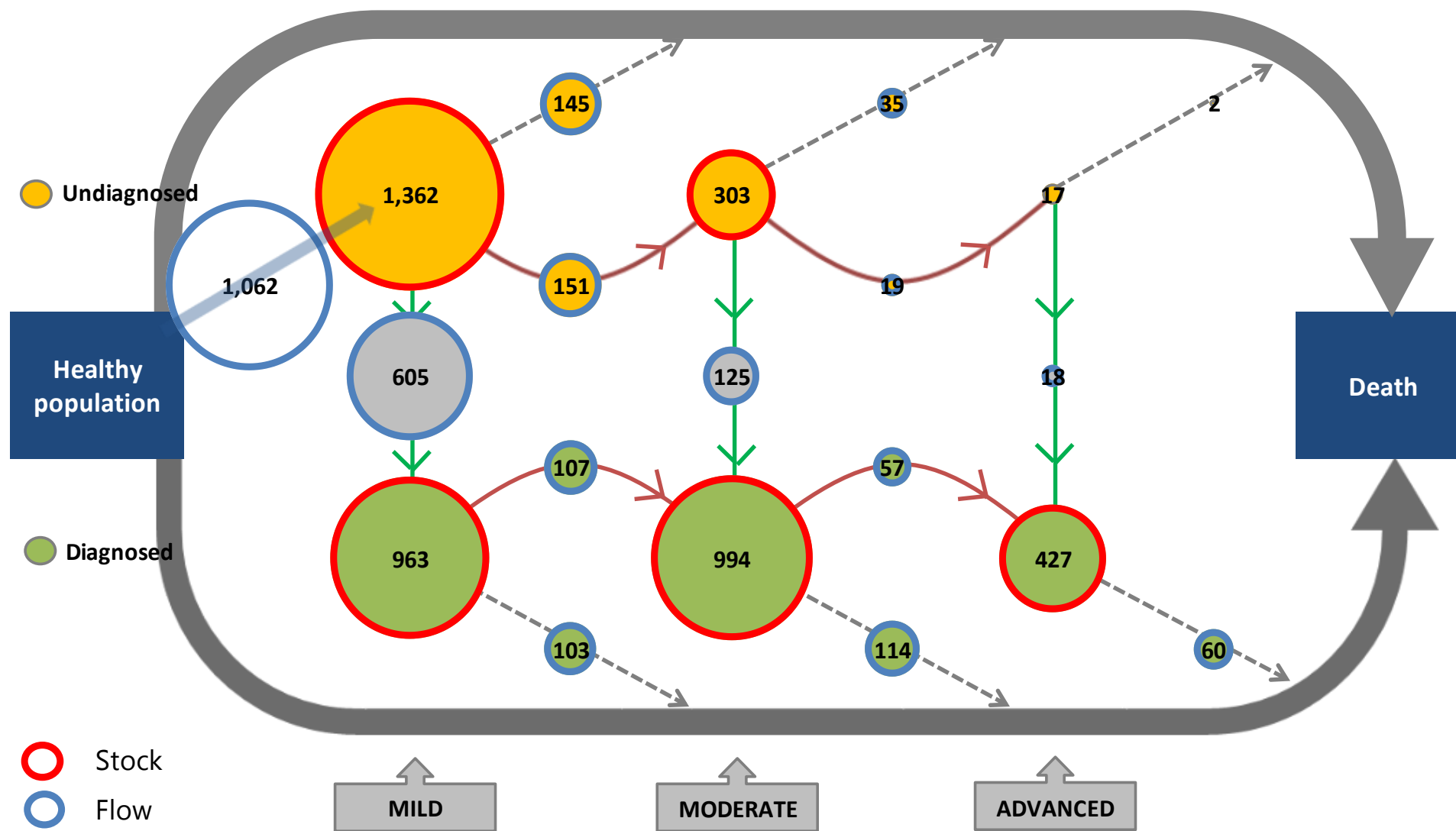
[9] Dementia UK: Second edition, Alzheimer's Society, September 2014

List of appendices

1. Markov model visualisations, 2014 and 2021.
2. Dementia pathway intervention points
3. Other resources and links
4. Markov model explained
5. Additional modelling assumptions

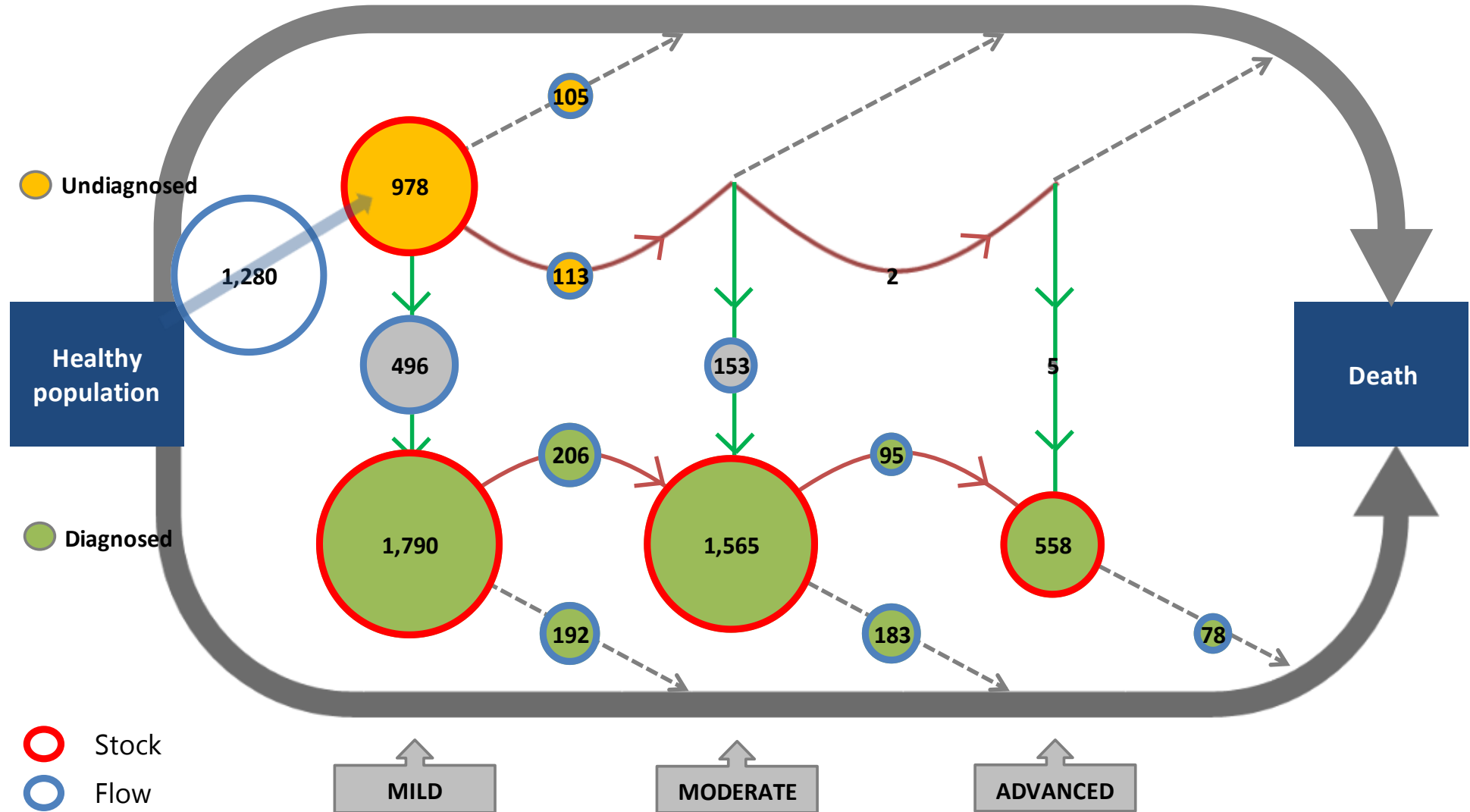
Appendix 1a: Markov Chain Model outputs: Baseline year (2014)

Dementia patient stocks and flows, 2014: [NHS Dudley](#)



Appendix 1b: Markov Chain Model outputs: Final year (2021)

Dementia patient stocks and flows, 2021: NHS Dudley



Appendix 2: Intervention points and management of disease

TIMELY ACCURATE DIAGNOSIS:

- Primary Care assessment & referral
- Self help information

Dementia patient stocks and flows, 2014: NHS Dudley

PRIMARY PREVENTION:

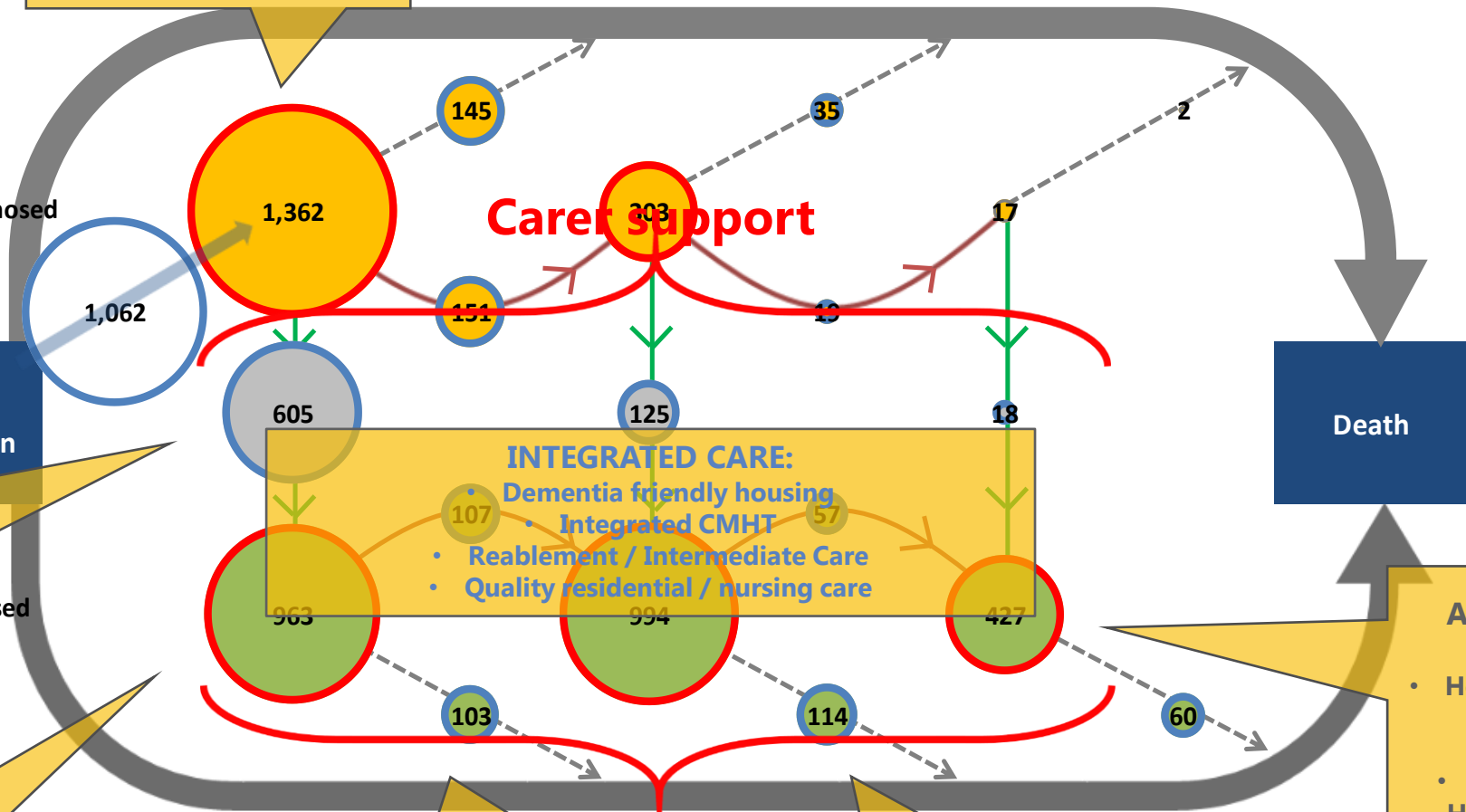
- Promote wellbeing
- 'Dementia Friendly'

MEMORY ASSESSMENT:

- Multi-disciplinary
- Expert diagnosis

ONGOING CARE:

- IAPT
- Genetic counselling
- Dental / Hearing / Sight checks



ADVANCED CARE:

- Home treatment / Crisis intervention
- Appropriate Home & Respite care

PALLIATIVE CARE:

- End-of-life
- Bereavement

Appendix 3: Other resources and useful links

Information and Intelligence:

1. Dementia Prevalence calculator -

<https://www.primarycare.nhs.uk/default.aspx>

Information and interactive reports of practice and higher-level reported and estimated prevalence snapshots (updated monthly).

2. Mental Health, Dementia and Neurology Intelligence Network -

<http://fingertips.phe.org.uk/profile-group/mental-health>

Series of profiles and reports on common or severe mental health, dementia and neurology conditions.

3. Health and Social Care Information Centre -

<http://www.hscic.gov.uk/dementia>

Range of information and reports on timely diagnosis, QOF, prescribing audits and the MHMDS in relation to Dementia.

Commissioning support:

4. West Midlands SCN -

<http://www.wmscnsenate.nhs.uk/strategic-clinical-network/our-network/mental-health-dementia-and-neurological-conditions/>

Information on current projects and commissioning resources available from the SCN.

5. National Institute for Health and Care Excellence -

<http://www.nice.org.uk/search?q=Dementia>

All the latest UK guidance, quality standards and evidence on Dementia from NICE.

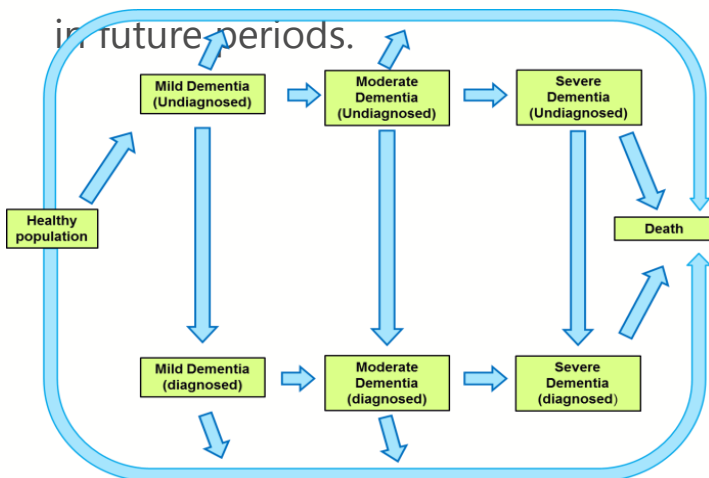
6. Dementia Partnerships' hub -

<http://dementiapartnerships.com/resource/dementia-commissioning-pack/>

Wide range of Dementia commissioning tools and templates grouped by stages and settings.

Appendix 4. Markov model explained

A Markov chain is a process with a finite number of states and dependent events. The likelihood of a patient moving from one state (e.g. Mild dementia, undiagnosed) to another (e.g. diagnosed) is generally pre-determined by available evidence or expert consensus. The 'flows' of patients through states are applied to the 'stocks' from previous periods (in this case a period = 1 year) in order to estimate the 'stocks' in future periods.



Specific formulae for our model:

Parameter	Ref	Derivation
Prevalent Cases – Mild,Moderate,Advanced	$P_{1,2,3}$	Population projection x
Prevalent Cases - Total	P	Age and gender specific dementia prevalence rates
Incident Cases	I	Population projection x Age and gender specific dementia incidence rates
Death of Prevalent Cases - Mild	D_1	Prevalent cases x Age and gender and CCG specific mortality rate
Death of Prevalent Cases - Moderate	D_2	
Death of Prevalent Cases - Advanced	D_3	
Death of Prevalent Cases - Total	D	
Prevalent Cases - Mild > Moderate	T_1	$T_1(t+1) = P_3(t+1) - P_3(t) + D_3(t+1)$
Prevalent Cases - Moderate > Advanced	T_2	$T_2(t+1) = P_2(t+1) - P_2(t) + D_2(t+1) + T_1(t+1)$
Diagnosed Cases - Mild	R_1	$R_1(t+1) = R(t+1) - R_2(t+1) - R_3(t+1)$
Diagnosed Cases - Moderate	R_2	$R_2(1) = 0.7$ $R_2(t+1) = (R_2(t)/(P_{32}(t) + 0.03) \times P_2(t+1)$
Diagnosed Cases - Advanced	R_3	$R_3(1) = 0.95$ $R_3(t+1) = (R_3(t)/(P_3(t) + 0.0053) \times P_3(t+1)$
Diagnosed Cases - Total	R	$R(t+1) = (R(t)/P(t) + 0.03) \times P(t+1)$
Diagnosed Cases - Mild > Moderate	S_1	$S_1(t+1) = P_1(t+1) \times R_1(t+1) / T_1(t+1)$
Diagnosed Cases - Moderate > Advanced	S_2	$S_2(t+1) = P_2(t+1) \times R_2(t+1) / T_2(t+1)$
Death of Diagnosed Cases - Mild	E_1	$E_1(t+1) = E(t+1) - E_2(t+1) - E_3(t+1)$
Death of Diagnosed Cases - Moderate	E_2	$E_2(t+1) = D_2(t+1) \times 0.8$
Death of Diagnosed Cases - Advanced	E_3	$E_3(t+1) = D_3(t+1) \times 0.95$
Death of Diagnosed Cases - Total	E	$E(t+1) = D(t+1) \times 0.8$
New Diagnoses – Mild,Moderate,Advanced	$N_{1,2,3}$	$N_1(t+1) = N(t+1) - N_2(t+1) - N_3(t+1)$
New Diagnoses - Total	N	$N(t+1) = E(t+1) + R(t+1) - R(t)$

Appendix 5: Additional assumptions used in the modelling

The aspirational diagnosis for 2015 is set at 67% in line with the National Dementia Challenge. Where current CCG diagnosis exceeds that, the current rate is used for maintenance purposes.

The aspirational diagnosis for 2021 is set arbitrarily at 80%.

Currently it is assumed that 70% of those with moderate disease and 95% of those with advanced disease are on disease registers. Both are assumed to be at 100% ascertainment by 2021.

That 20% of dementia patients die before formal diagnosis. This remains unchanged to 2021.

That the rates of all cause mortality by CCG follow the same distribution as Dementia specific mortality rates by CCG.

That the distribution of the over 85 projected population for England & Wales is the same for each CCG.

That the number of practices per CCG will remain the same up to 2021.

That the sub-types of Dementia follow the same distribution for each CCG.

The adjustment to nursing home dementia patients for changes in population prevalence of moderate/severe cases to 2021 only apply to non Local Authority care homes.



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