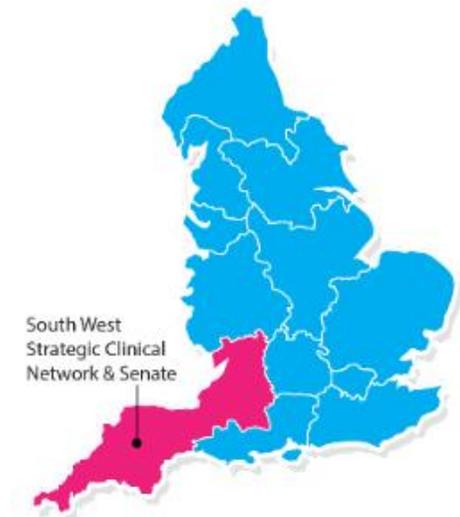


Young Onset and Rare Dementias Service Mapping in the South West



Young Onset and Rare Dementias Service Mapping in the South West

Prepared by: The South West Strategic Clinical Network for Mental Health, Dementia & Neurological Conditions between March 2015 and June 2015.

How many patients are you aware of in your area with young onset dementia age <65 years old at time of diagnosis for the sake of comparability?	
<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service Liskeard</p>	154 (numbers taken from a recent audit) across Cornwall
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	241<65 years. 3 new referrals from GPS in April 2015. 34 people with Huntington's Disease (NB: I'm not sure if they are all >65).
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>Looking at last year's figures we estimate that of the total number of service users diagnosed with Young Onset Dementia (YOD) in the secondary Memory service was 9.5% of a total number of 228 who were diagnosed. In the same period those diagnosed with YOD in the Complex Intervention and Therapies team is thought to be 1.2% of a total number of 278 referrals (It is thought that the majority of people diagnosed with YOD in the CITT are dementias related to alcohol).</p> <p>These figures are not representative of all the people in South Glos who have been diagnosed with YON in the last year, because it is thought that a significant number of people diagnosed receive their diagnosis from Neurology.</p>

<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>Circa 70. Using estimates from prevalence studies, we would expect circa 180 for DPT.</p> <table border="1" data-bbox="510 328 1151 866"> <thead> <tr> <th rowspan="2">Diagnosis</th> <th colspan="10">Age at diagnosis</th> <th rowspan="2">Total</th> </tr> <tr> <th>15-19</th> <th>20-24</th> <th>25-29</th> <th>30-34</th> <th>35-39</th> <th>40-44</th> <th>45-49</th> <th>50-54</th> <th>55-59</th> <th>60-64</th> </tr> </thead> <tbody> <tr><td>Alzheimer's disease with early onset</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>1</td></tr> <tr><td>Alzheimer's disease, unspecified</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>1</td></tr> <tr><td>Delirium not superimposed on dementia, so described</td><td></td><td>1</td><td></td><td></td><td>1</td><td></td><td>1</td><td></td><td>6</td><td>2</td><td>11</td><td></td></tr> <tr><td>Delirium superimposed on dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td>1</td><td>2</td><td></td></tr> <tr><td>Dementia in Alzheimer's disease</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>1</td><td></td></tr> <tr><td>Dementia in Alzheimer's disease with early onset</td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>4</td><td>13</td><td>29</td><td>51</td><td>99</td><td></td></tr> <tr><td>Dementia in Alzheimer's disease with late onset</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>4</td><td>5</td><td></td></tr> <tr><td>Dementia in Alzheimer's disease, atypical or mixed type</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>2</td><td>22</td><td>26</td><td></td></tr> <tr><td>Dementia in Alzheimer's disease, unspecified</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>2</td><td>5</td><td>8</td><td></td></tr> <tr><td>Dementia in Creutzfeldt-Jakob disease</td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td></td><td></td><td></td><td>1</td><td></td></tr> <tr><td>Dementia in human immunodeficiency virus (HIV) disease</td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td></td><td></td><td></td><td>1</td><td></td></tr> <tr><td>Dementia in Huntingtons disease</td><td></td><td></td><td>1</td><td></td><td></td><td></td><td>1</td><td></td><td></td><td>5</td><td>7</td><td></td></tr> <tr><td>Dementia in other specified diseases classified elsewhere</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>1</td><td>6</td><td>9</td><td></td></tr> <tr><td>Dementia in Parkinsons disease</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>4</td><td>5</td><td></td></tr> <tr><td>Dementia in Pick's disease</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>5</td><td>7</td><td>14</td><td></td></tr> <tr><td>Mixed cortical and subcortical vascular dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>3</td><td>3</td><td></td></tr> <tr><td>Multi-infarct dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>1</td><td>3</td><td>6</td><td></td></tr> <tr><td>Other vascular dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>1</td><td>6</td><td>9</td><td></td></tr> <tr><td>Subcortical vascular dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td></td><td></td><td>1</td><td></td></tr> <tr><td>Unspecified dementia</td><td></td><td></td><td></td><td></td><td>1</td><td></td><td>2</td><td>8</td><td>9</td><td>16</td><td>36</td><td></td></tr> <tr><td>Vascular dementia of acute onset</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td>1</td><td>2</td><td></td></tr> <tr><td>Vascular dementia, unspecified</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>5</td><td>8</td><td>15</td><td></td></tr> <tr><td>Total</td><td>0</td><td>1</td><td>1</td><td>0</td><td>2</td><td>4</td><td>9</td><td>36</td><td>63</td><td>147</td><td>263</td><td></td></tr> </tbody> </table>	Diagnosis	Age at diagnosis										Total	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	Alzheimer's disease with early onset											1	1	Alzheimer's disease, unspecified											1	1	Delirium not superimposed on dementia, so described		1			1		1		6	2	11		Delirium superimposed on dementia								1		1	2		Dementia in Alzheimer's disease										1	1		Dementia in Alzheimer's disease with early onset						2	4	13	29	51	99		Dementia in Alzheimer's disease with late onset									1	4	5		Dementia in Alzheimer's disease, atypical or mixed type								2	2	22	26		Dementia in Alzheimer's disease, unspecified								1	2	5	8		Dementia in Creutzfeldt-Jakob disease						1					1		Dementia in human immunodeficiency virus (HIV) disease						1					1		Dementia in Huntingtons disease			1				1			5	7		Dementia in other specified diseases classified elsewhere								2	1	6	9		Dementia in Parkinsons disease									1	4	5		Dementia in Pick's disease								2	5	7	14		Mixed cortical and subcortical vascular dementia										3	3		Multi-infarct dementia								2	1	3	6		Other vascular dementia								2	1	6	9		Subcortical vascular dementia							1				1		Unspecified dementia					1		2	8	9	16	36		Vascular dementia of acute onset								1		1	2		Vascular dementia, unspecified								2	5	8	15		Total	0	1	1	0	2	4	9	36	63	147	263	
Diagnosis	Age at diagnosis										Total																																																																																																																																																																																																																																																																																																																							
	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64																																																																																																																																																																																																																																																																																																																								
Alzheimer's disease with early onset											1	1																																																																																																																																																																																																																																																																																																																						
Alzheimer's disease, unspecified											1	1																																																																																																																																																																																																																																																																																																																						
Delirium not superimposed on dementia, so described		1			1		1		6	2	11																																																																																																																																																																																																																																																																																																																							
Delirium superimposed on dementia								1		1	2																																																																																																																																																																																																																																																																																																																							
Dementia in Alzheimer's disease										1	1																																																																																																																																																																																																																																																																																																																							
Dementia in Alzheimer's disease with early onset						2	4	13	29	51	99																																																																																																																																																																																																																																																																																																																							
Dementia in Alzheimer's disease with late onset									1	4	5																																																																																																																																																																																																																																																																																																																							
Dementia in Alzheimer's disease, atypical or mixed type								2	2	22	26																																																																																																																																																																																																																																																																																																																							
Dementia in Alzheimer's disease, unspecified								1	2	5	8																																																																																																																																																																																																																																																																																																																							
Dementia in Creutzfeldt-Jakob disease						1					1																																																																																																																																																																																																																																																																																																																							
Dementia in human immunodeficiency virus (HIV) disease						1					1																																																																																																																																																																																																																																																																																																																							
Dementia in Huntingtons disease			1				1			5	7																																																																																																																																																																																																																																																																																																																							
Dementia in other specified diseases classified elsewhere								2	1	6	9																																																																																																																																																																																																																																																																																																																							
Dementia in Parkinsons disease									1	4	5																																																																																																																																																																																																																																																																																																																							
Dementia in Pick's disease								2	5	7	14																																																																																																																																																																																																																																																																																																																							
Mixed cortical and subcortical vascular dementia										3	3																																																																																																																																																																																																																																																																																																																							
Multi-infarct dementia								2	1	3	6																																																																																																																																																																																																																																																																																																																							
Other vascular dementia								2	1	6	9																																																																																																																																																																																																																																																																																																																							
Subcortical vascular dementia							1				1																																																																																																																																																																																																																																																																																																																							
Unspecified dementia					1		2	8	9	16	36																																																																																																																																																																																																																																																																																																																							
Vascular dementia of acute onset								1		1	2																																																																																																																																																																																																																																																																																																																							
Vascular dementia, unspecified								2	5	8	15																																																																																																																																																																																																																																																																																																																							
Total	0	1	1	0	2	4	9	36	63	147	263																																																																																																																																																																																																																																																																																																																							
<p>Somerset Completed by a number of different people</p>	<p>Approximately 106 patients</p>																																																																																																																																																																																																																																																																																																																																	
<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>Approximately 50 people in Swindon (only estimates are based on national prevalence from Dementia JSNA in 2012). Anecdotally numbers are increasing – actual numbers will be available from AWP.</p>																																																																																																																																																																																																																																																																																																																																	
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>We have a rough estimate of 53 clients from recent review of the current service provision. These numbers however will be 'just the tip of the iceberg'.</p> <p>Recent data review from the office of national statistics population projections suggest that in 2015 the population of Cheltenham and Gloucester will be c0.7M people with an estimated 500 cases and by 2025 this will be c0.8M with a corresponding increase in cases.</p>																																																																																																																																																																																																																																																																																																																																	

<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>Of the referrals between 2011 and 2014, 215 people under 65 were diagnosed with dementia (aged 27-64). We cannot provide more recent exact numbers at present however have stats that suggest we see an average of 250 per year under 75 years of age.</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>5</p>
<p>North Somerset Memory Service Completed by Kay Stokes, Manager</p>	<p>From May 2011 – March 2015. 144 people under 65 referred to the memory service.</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (OPMH) Functional Community Team (Plym Locality)</p>	<p>27 in the past 12 months</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>A review of patients seen at RICE in 2013 showed 5% of referrals are under 65. We are aware of approximately 65 people who were diagnosed before the age of 65 – however many of these are now much older. There will be other young onset patients in the area who are being seen by other specialties and this will depend on where their GPs choose to refer them. Predominantly behavioural problems (eg bvFTD) may go to the mental health team and neurological problems (eg CJD of HD) to the neurologists.</p>

<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Unable to provide accurate figures</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Depends on definition of dementia. If you include cognitive impairment related to neurological conditions that significantly impacts on daily functioning then I would roughly estimate it to be around 100 hundred in BANES</p>

How many patients are you aware of in your area with rare dementias (e.g. HD, PD, MS, normal pressure hydrocephalus, CJD, Korsakoffs, Picks disease)?

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service Liskeard</p>																																																																																																																																																																																																																																																																																																																						
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>																																																																																																																																																																																																																																																																																																																						
<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<table border="1"> <thead> <tr> <th rowspan="2">Diagnosis</th> <th colspan="10">Age at diagnosis</th> <th rowspan="2">Total</th> </tr> <tr> <th>15-19</th> <th>20-24</th> <th>25-29</th> <th>30-34</th> <th>35-39</th> <th>40-44</th> <th>45-49</th> <th>50-54</th> <th>55-59</th> <th>60-64</th> </tr> </thead> <tbody> <tr><td>Alzheimer's disease with early onset</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>1</td></tr> <tr><td>Alzheimer's disease, unspecified</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>1</td></tr> <tr><td>Delirium not superimposed on dementia, so described</td><td></td><td>1</td><td></td><td></td><td>1</td><td></td><td>1</td><td></td><td>6</td><td>2</td><td>11</td></tr> <tr><td>Delirium superimposed on dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td>1</td><td>2</td></tr> <tr><td>Dementia in Alzheimer's disease</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>1</td></tr> <tr><td>Dementia in Alzheimer's disease with early onset</td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>4</td><td>13</td><td>29</td><td>51</td><td>99</td></tr> <tr><td>Dementia in Alzheimer's disease with late onset</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>4</td><td>5</td></tr> <tr><td>Dementia in Alzheimer's disease, atypical or mixed type</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>2</td><td>22</td><td>26</td></tr> <tr><td>Dementia in Alzheimer's disease, unspecified</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>2</td><td>5</td><td>8</td></tr> <tr><td>Dementia in Creutzfeldt-Jakob disease</td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td></td><td></td><td></td><td>1</td></tr> <tr><td>Dementia in human immunodeficiency virus (HIV) disease</td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td></td><td></td><td></td><td>1</td></tr> <tr><td>Dementia in Huntington's disease</td><td></td><td></td><td>1</td><td></td><td></td><td></td><td>1</td><td></td><td></td><td>5</td><td>7</td></tr> <tr><td>Dementia in other specified diseases classified elsewhere</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>1</td><td>6</td><td>9</td></tr> <tr><td>Dementia in Parkinson's disease</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td>4</td><td>5</td></tr> <tr><td>Dementia in Pick's disease</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>5</td><td>7</td><td>14</td></tr> <tr><td>Mixed cortical and subcortical vascular dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>3</td><td>3</td></tr> <tr><td>Multi-infarct dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>1</td><td>3</td><td>6</td></tr> <tr><td>Other vascular dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>1</td><td>6</td><td>9</td></tr> <tr><td>Subcortical vascular dementia</td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td></td><td></td><td>1</td></tr> <tr><td>Unspecified dementia</td><td></td><td></td><td></td><td></td><td>1</td><td></td><td>2</td><td>8</td><td>9</td><td>16</td><td>36</td></tr> <tr><td>Vascular dementia of acute onset</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>1</td><td></td><td>1</td><td>2</td></tr> <tr><td>Vascular dementia, unspecified</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>2</td><td>5</td><td>8</td><td>15</td></tr> <tr><td>Total</td><td>0</td><td>1</td><td>1</td><td>0</td><td>2</td><td>4</td><td>9</td><td>36</td><td>63</td><td>147</td><td>263</td></tr> </tbody> </table>											Diagnosis	Age at diagnosis										Total	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	Alzheimer's disease with early onset										1	1	Alzheimer's disease, unspecified										1	1	Delirium not superimposed on dementia, so described		1			1		1		6	2	11	Delirium superimposed on dementia								1		1	2	Dementia in Alzheimer's disease										1	1	Dementia in Alzheimer's disease with early onset						2	4	13	29	51	99	Dementia in Alzheimer's disease with late onset									1	4	5	Dementia in Alzheimer's disease, atypical or mixed type								2	2	22	26	Dementia in Alzheimer's disease, unspecified								1	2	5	8	Dementia in Creutzfeldt-Jakob disease						1					1	Dementia in human immunodeficiency virus (HIV) disease						1					1	Dementia in Huntington's disease			1				1			5	7	Dementia in other specified diseases classified elsewhere								2	1	6	9	Dementia in Parkinson's disease									1	4	5	Dementia in Pick's disease								2	5	7	14	Mixed cortical and subcortical vascular dementia										3	3	Multi-infarct dementia								2	1	3	6	Other vascular dementia								2	1	6	9	Subcortical vascular dementia							1				1	Unspecified dementia					1		2	8	9	16	36	Vascular dementia of acute onset								1		1	2	Vascular dementia, unspecified								2	5	8	15	Total	0	1	1	0	2	4	9	36	63	147	263	<p>Unknown, but very few</p>
Diagnosis	Age at diagnosis										Total																																																																																																																																																																																																																																																																																																											
	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64																																																																																																																																																																																																																																																																																																												
Alzheimer's disease with early onset										1	1																																																																																																																																																																																																																																																																																																											
Alzheimer's disease, unspecified										1	1																																																																																																																																																																																																																																																																																																											
Delirium not superimposed on dementia, so described		1			1		1		6	2	11																																																																																																																																																																																																																																																																																																											
Delirium superimposed on dementia								1		1	2																																																																																																																																																																																																																																																																																																											
Dementia in Alzheimer's disease										1	1																																																																																																																																																																																																																																																																																																											
Dementia in Alzheimer's disease with early onset						2	4	13	29	51	99																																																																																																																																																																																																																																																																																																											
Dementia in Alzheimer's disease with late onset									1	4	5																																																																																																																																																																																																																																																																																																											
Dementia in Alzheimer's disease, atypical or mixed type								2	2	22	26																																																																																																																																																																																																																																																																																																											
Dementia in Alzheimer's disease, unspecified								1	2	5	8																																																																																																																																																																																																																																																																																																											
Dementia in Creutzfeldt-Jakob disease						1					1																																																																																																																																																																																																																																																																																																											
Dementia in human immunodeficiency virus (HIV) disease						1					1																																																																																																																																																																																																																																																																																																											
Dementia in Huntington's disease			1				1			5	7																																																																																																																																																																																																																																																																																																											
Dementia in other specified diseases classified elsewhere								2	1	6	9																																																																																																																																																																																																																																																																																																											
Dementia in Parkinson's disease									1	4	5																																																																																																																																																																																																																																																																																																											
Dementia in Pick's disease								2	5	7	14																																																																																																																																																																																																																																																																																																											
Mixed cortical and subcortical vascular dementia										3	3																																																																																																																																																																																																																																																																																																											
Multi-infarct dementia								2	1	3	6																																																																																																																																																																																																																																																																																																											
Other vascular dementia								2	1	6	9																																																																																																																																																																																																																																																																																																											
Subcortical vascular dementia							1				1																																																																																																																																																																																																																																																																																																											
Unspecified dementia					1		2	8	9	16	36																																																																																																																																																																																																																																																																																																											
Vascular dementia of acute onset								1		1	2																																																																																																																																																																																																																																																																																																											
Vascular dementia, unspecified								2	5	8	15																																																																																																																																																																																																																																																																																																											
Total	0	1	1	0	2	4	9	36	63	147	263																																																																																																																																																																																																																																																																																																											
<p>Somerset Completed by a number of different people</p>																																																																																																																																																																																																																																																																																																																						

<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>Numbers are applied prevalence rates – not actual.</p> <table border="1" data-bbox="831 312 1464 619"> <thead> <tr> <th>Table 4: Estimates of type of dementia-Type of dementia</th> <th>Proportion of people with dementia (Dementia-UK-2007:15)</th> <th>Proportions applied to Swindon (SBC boundaries) Age 65+ population</th> <th></th> </tr> </thead> <tbody> <tr> <td>Alzheimer's Disease</td> <td>62%</td> <td>1293</td> <td></td> </tr> <tr> <td>Vascular dementia</td> <td>17%</td> <td>355</td> <td></td> </tr> <tr> <td>Mixed (AD and VD)</td> <td>10%</td> <td>209</td> <td></td> </tr> <tr> <td>Dementia with Lewy bodies</td> <td>4%</td> <td>83</td> <td></td> </tr> <tr> <td>Frontotemporal dementia</td> <td>2%</td> <td>42</td> <td></td> </tr> <tr> <td>Parkinson's dementia</td> <td>2%</td> <td>42</td> <td></td> </tr> <tr> <td>Other</td> <td>3%</td> <td>63</td> <td></td> </tr> <tr> <td>Total</td> <td></td> <td>2085</td> <td></td> </tr> </tbody> </table> <p>¶ </p>	Table 4: Estimates of type of dementia-Type of dementia	Proportion of people with dementia (Dementia-UK-2007:15)	Proportions applied to Swindon (SBC boundaries) Age 65+ population		Alzheimer's Disease	62%	1293		Vascular dementia	17%	355		Mixed (AD and VD)	10%	209		Dementia with Lewy bodies	4%	83		Frontotemporal dementia	2%	42		Parkinson's dementia	2%	42		Other	3%	63		Total		2085	
Table 4: Estimates of type of dementia-Type of dementia	Proportion of people with dementia (Dementia-UK-2007:15)	Proportions applied to Swindon (SBC boundaries) Age 65+ population																																			
Alzheimer's Disease	62%	1293																																			
Vascular dementia	17%	355																																			
Mixed (AD and VD)	10%	209																																			
Dementia with Lewy bodies	4%	83																																			
Frontotemporal dementia	2%	42																																			
Parkinson's dementia	2%	42																																			
Other	3%	63																																			
Total		2085																																			
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>It is difficult to determine these numbers as our current data collection through the RIO system is not sensitive enough to pick up all our diagnosis data. We are working on improving our data collection.</p>																																				
<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>YPWD approx. 50% rare dementias the remaining 50% = AD</p> <p>Comment: Picks = FTD more appropriate term Majority of the other named conditions aren't necessarily dementias in their own right.</p>																																				
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>2</p>																																				

<p>North Somerset Memory Service Completed by Kay Stokes, Manager</p>	<p>144 people under 65 referred to the memory service.</p> <p>Of which;</p> <ul style="list-style-type: none"> • Mild Cognitive Impairment – 77 • Alzheimer’s Disease – 26 • Vascular dementia – 9 • Fronto Temporal Dementia – 6 • Dementia in Parkinson’s – 2 <p>Total with a diagnosis = 121.</p> <p>Outstanding number of patients 23 with no formal diagnosis of a cognitive impairment – outcome of depression, anxiety etc.</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People’s Mental Health (<i>OPMH</i>) Functional Community Team (Plym Locality)</p>	<p>No data available</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>We feel there is a need to be specific about the definition of rare eg we would not consider PD dementia rare whereas we would consider Semantic dementia (one of the FTDs) and Huntington’s dementia as rare.</p> <p>We are aware of around 50 people in our area but there will be others who are known to other specialties especially the neurologists and mental health teams</p>
<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>In the last 2 years (personal figures). Difficult to provide accurate figures</p> <p>CJD – 1 PCA – 3 HD – 3 NPH – 4 – (2 shunted, 2 further investigations) MS – a fair few number I suspect FTD - 2</p>

Sirona Care & Health CIC- Bath & North East Somerset
Submitted by Laura Marsh
Commissioning Manager for Long Term Conditions
BaNES CCG

Only aware of one actual diagnosed HIV related dementia but we are also aware of a significant number of patients with neurological conditions and associated cognitive decline.

Who is making diagnosis in younger patients? E.g. Memory Clinic, Neurologist, Care of the Elderly, other.

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service Liskeard</p>	<p>Diagnosis is usually made either by Memory Clinics or Neurologist</p>
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	<p>Neurology, secondary health services Memory Assessment Clinic</p>
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>Memory Service, Neurology and CITT.</p>
<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>Old age psychiatrists, neurologists(especially Prof Ziemann), Geriatricians</p>
<p>Somerset Completed by a number of different people</p>	<p>The pathway in Somerset is for patients to be referred to the Memory Assessment Service.</p>
<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>Memory Clinic</p>
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>Consultant Psychiatrists, Neurologists</p>

<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>Majority of YPWD are diagnosed via our Specialist Memory Clinic. Very occasionally individuals will access our service via GP if diagnosed elsewhere – often seeking confirmation of diagnosis and/ or need for on-going review. We are unable to comment on whether neurology / care of elderly diagnose as they are separate services / NHS trusts to ours however presumably this is the case – particularly with neuro.</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>Memory Clinic</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (<i>OPMH</i>) Functional Community Team (Plym Locality)</p>	<p>Memory Clinic Consultant Psychiatrist, following triage process at MDT or following Memory Nurse assessment</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>We usually make the diagnosis in patients referred to us.</p> <p>GPs may be referring to other specialties regarding a diagnosis. These include:</p> <ul style="list-style-type: none"> • Parkinson's disease - neurologists or Movement disorder team • Huntington's and CJD – neurologists • MS - neurologists and Community Neuro and Stroke Service) • NPH - Bristol neurosurgeons • Korsakoffs - Mental health team • Picks - Mental health team
<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Neurologist (all three)</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Not sure but I suspect it would be GP's, Neurologists and movement disorder specialists.</p>

Which subtypes of dementia would you associate with younger onset based on recent diagnostic experience?

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service Liskeard</p>	<p>Usually Alzheimer's disease, vascular dementia, fronto-temporal and alcohol related dementia - in that order.</p>
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	<p>Korsakoff's, Huntington's, CVD.</p>
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>Alzheimer's Disease and Frontal-temporal dementia.</p>
<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>Alzheimer's most common.</p>
<p>Somerset Completed by a number of different people</p>	<p>All, but Fronto-temporal and Parkinsonian may be over represented although this is anecdotal and has not been studied.</p>
<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>From Dementia JSNA 2012:</p> <p>It is estimated that about 10% of dementias in younger people are alcohol related; abstinence, high doses of B1, an improved diet and increased support people can show improvement. Korsakoffs syndrome is caused by a lack of vitamin B1 in the body brought on by heavy alcohol consumption over a long term. There is also some debate whether alcoholic's dementia is a separate condition. Both of these are different from usual dementias. The 2009 Swindon Alcohol Health Needs Assessment reviews the current picture of alcohol in Swindon from a public health perspective (a wider definition of "health" which includes wider social and economic factors including criminal offending) and notes a number of key headline facts about Swindon. It is estimated that:</p> <ul style="list-style-type: none"> - 20% of Swindon residents aged 16 years and over engage in hazardous drinking, defined as consumption of between 22 and 50 units of alcohol per week for men, and 15 and 35 unites of alcohol per week for women - 4.9% of Swindon residents aged 16 years and over say that they engage in harmful drinking (more than 50 units of alcohol per week for men, and more than 35 units of alcohol per week for women) - 16.1% of adults in Swindon engage in binge drinking (consuming at least twice the daily recommended amount of alcohol). - Swindon's Rough Sleeper Panel estimates that 95% of those sleeping rough have alcohol and drugs issues.

<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>FTD (LPA, PPA, Semantic, Behaviour Variant, Motor Neurone with FTD), Alzheimer's (PCA) Vascular (CASADIL), Korsakoffs Syndrome, Lewy Body, Parkinson Disease Dementia.</p>
<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>AD CADASIL (VD) – familial / genetic + links with depression / mental health Fronto-temporal dementia Posterior cortical atrophy</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>None (mixed).</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (OPMH) Functional Community Team (Plym Locality)</p>	<p>Korsakoffs</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>AD, PCA, Semantic dementia, Primary progressive aphasia, behavioural FTD, DLB.</p>
<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>In the last 2 years (personal figures). Difficult to provide accurate figures CJD – 1 PCA – 3 HD – 3 NPH – 4 – (2 shunted, 2 further investigations) MS – a fair few number I suspect FTD - 2</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Not sure. If you include cognitive decline that is associated with a neurological condition and impacts on daily living then I would include Parkinsons disease, MS, MND, Head injury, Stroke. Others may include early onset Alzheimers, frontotemporal dementias</p>

What information is provided to patients at diagnosis? Specifically please:

- About the condition diagnosed and,
- About prognosis (time to no longer being able to work, time to institutionalisation, life expectancy) and,
- About sources of specific advice on employment, legal aspects (e.g. advance care planning, driving) and benefit eligibility.

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service Liskeard</p>	<p>If diagnosed by Memory Clinics they would receive an information pack which covers;</p> <ul style="list-style-type: none"> - Diagnosis and prognosis - Cognitive Stimulation Therapy - Driving and transport - Legal affairs and benefits - Carers Support - Assistive Technology - Contacts - Advance care planning and end of life care - Taking part in research. 	<p>This would be followed up by a visit post diagnostic counselling visit to discuss the diagnosis and prognosis in more detail.</p> <p>In Cornwall Foundation Trust our OTs tend to assess and care co-ordinate younger people with dementia, to maintain patients' independence in all activities of daily living (including employment) and maintain their quality of life. The Lead Occupational Therapist has worked primarily with Younger People with Dementia for the last 17 years – current caseload 7 patients.</p>
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	<p>All of above – individualised info pack given out at MAS – not sure what is given out in neurology.</p>	
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>In the Memory Service at the time of diagnosis patients with YOD are provided with information about:</p> <ul style="list-style-type: none"> - The condition diagnosed and prognosis. - There would be discussion about continuing with work, the possibility of institutional care and life expectancy on a case by case basis if appropriate. - Information and advice is regularly provided about benefit eligibility, driving and legal aspects. 	<p>We rarely provide advice about employment and in the last year have only been asked to provide a 2nd opinion to a Service Users (SU) occupational health scheme on one occasion. We frequently refer our SU's to Age UK based in Thornbury, who run an excellent, person centred service supporting people with for advice about accessing legal services and benefit eligibility.</p>
<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>Depends on their diagnosis, but they would be treated as per standard dementia care protocols, adjusting this to meet their particular needs.</p>	
<p>Somerset Completed by a number of different people</p>	<p>At diagnosis, information is provided about the condition diagnosed. An individual approach is taken re: information around prognosis. Information about sources of specific advice e.g. employment is also given.</p>	

<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>AWP / SCCG to answer</p>
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>Diagnostic Investigation are conducted through our Managing memory assessment team and at the point of diagnosis people are provided with a post diagnostic appointment where there is discussion on the persons diagnosis; what it means, progression, any possible treatment options to assist with symptoms, advice on relevant legal aspects always utilising advance care planning where possible, driving advice and is tailored to the needs of the individual. Further resources are provided through the managing memory education resource.</p>
<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>Dependent on what SU's want to know – it is totally client led; people are not given a set pack of information. Each person is however provided with something as well as an invitation to accept a post diagnostic visit to revisit the information that has been offered to them, give another opportunity to ask questions that they may not have thought about initially.</p> <p>We always give information about the diagnosis, driving (if relevant), legal advice, general wellbeing, advance care planning and benefits and we signpost to relevant services.</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>Not known</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (OPMH) Functional Community Team (Plym Locality)</p>	<p>'What now pack' – information pack which signposts to Organisations, community support, etc.</p> <p>The Consultant talks through with the patient the diagnosis but no specific literature on early onset dementia is routinely given.</p>

<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Verbal information – RICE staff will aim to cover all 3 items.</p> <p>Written information – RICE leaflets and information from other organisations eg the Alzheimer’s Society, the BANES Information Prescription. We have a large range of leaflets and booklets available in the waiting area. Where appropriate we will download information or recommend websites.</p> <p>We routinely involve the Alzheimer’s society Dementia support workers who attend our clinics. They will cover all 3 areas in more detail and follow up over time especially as circumstances and needs change.</p> <p>We have a clinical psychologist (unfunded) who provides post diagnostic counselling.</p> <p>We refer to the Carers Centre where appropriate.</p> <p>We liaise with other specialties and the Mental Health team where appropriate.</p>
<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>At diagnosis – tend to address issues regarding the diagnosis and prognosis but in general terms. Discuss issues further at follow-up appointments.</p> <p>I do not discuss life expectancy unless someone with CJD. I do not discuss the other issues at time of diagnosis.</p> <p>I do discuss driving and advance care planning with all patients at diagnosis.</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Not sure as our service does not diagnose dementia</p>

What support is then offered? Please specify whether the support types are generic/integrated (for all people with dementia irrespective of age) or specific (for young onset people only), and who provides them:

- Acute hospital/outpatients
- GP/Primary Care Team
- Mental health provider
- Other commissioned support provider (e.g. Dementia Adviser service, Huntingdon's Disease nurse)
- Voluntary sector services (e.g. Memory Café, local Young Onset Dementia support group)

<p>Cornwall Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service Liskeard</p>	<p>On-going support would usually be from within CFT (secondary care):</p> <ul style="list-style-type: none"> - OT or Memory Assessment Nurse. Support is not young person specific. - We have Admiral Nurses for carers, they are charity funded <p>From the voluntary sector:</p> <ul style="list-style-type: none"> - Memory Café's, a local young on-set support group for carers (East Cornwall only) and a frontotemporal support group (East and West Cornwall) 	
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	<p>Ageless support – 8 week group or 1:1 CST, maintenance CST, memory cafes, usual mainstream services – CMHT, Primary care Dementia Practitioners, Dementia Support Workers, Admiral Nurses, Dementia Carer Support, Dementia Liaison (hospital and care home), Memory Clinics, Memory cafes.</p>	<p>As far as I'm aware there is one young onset support group for people with dementia and one for carers. There are some individual opportunities for people too – attending Cornwall Dementia Leadership group, giving ad-hoc talks, sitting on Hospital Dementia Action group. Huntington's Disease led OP and outreach clinic.</p>

<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>Following diagnosis within the Secondary Memory Service all SU's irrespective of age are offered specialist post diagnostic support and advice.</p> <p>This may be on a 1:1 basis or more commonly in a specialist post diagnostic Group.</p> <p>Prior to attending the post diagnostic Group all attendees are visited and age is considered in terms of what the individual will gain to ensure that needs are met. The post diagnostic Group and 1:1 support is also available for SU's seen in the Primary service at the request of the GP.</p> <p>A recent focus group (February 2015) was carried out with People with YOD diagnosed within the Memory service to establish what they felt they needed in terms of post diagnostic support. They were clear that a specific Dementia Road show for younger people was not required at this stage. Those consulted were also given the opportunity to get together with others to determine if they wanted an on-going younger people's group. This was declined at this time, but will be reviewed in 6/12. There was discussion about whether there should be a Memory café specifically for younger people and this too was felt to be not necessary at this time, as their needs were being met in other ways.</p>	<p>Following the completion of most post diagnostic support Groups within the Memory service many 'graduates' continue to meet together on a regular basis within the community .This is regarded by those consulted as providing effective peer support. The focus group expressed that they would be prepared to act as peer mentors for other young people with dementia receiving a diagnosis with some group facilitation initially by the Memory service. The younger people with dementia consulted felt that provision of services/support should be primarily 'needs led' rather than focusing on other factors such as age; whilst acknowledging that factors associated with age could be an issue, for example working partners, young children and so on. Overwhelmingly people wanted to be with others who were in a similar place in the progression of their illness.</p> <p>The Alzheimer's Society runs a Day resource 'The Limes' specifically catering for people with YOD in East Bristol. This facility serves: Bristol, S Glos, BAINES and N. Somerset. Approximately 1/3 of their attendees are currently S. Glos residents. The Limes operates between 08.00 and 18.00 Monday to Friday and has the capacity to take up to 9 clients per day. The Limes has a high ratio of staff to clients: 1:3 and all staff are experienced and highly trained in dementia care. The emphasis of this facility is on improving the health and wellbeing of their client group. Referrals can be made by individuals themselves and are not dependant on the local authority. The Limes supports clients with abilities across the spectrum of needs and because of its high staff to client ratio can support people with a high level of need.</p> <p>A number of Memory cafes exist across S Glos, these are located in: Winterbourne, Hanham, Yate, Emerson's Green, Patchway and Thornbury, all are run by the Alzheimer's Society apart from the latter which is independently run. Although some people with YOD and their carers attend these cafes their attendees tend to be mainly made up from older people with Dementia. The emphasis of the Memory cafes is to support the carers of people with dementia.</p>
<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>There is no young onset specific service, but young onset cases can be referred for specialist opinion (often Prof Ziemann – Neurology).</p>	

<p>Somerset Completed by a number of different people</p>	<p>The Alzheimer's Society services are accessible to young people with a diagnosis. A CrISP course for Younger People with Dementia is available. Also in South Somerset there is a Young at Heart Group set up for younger people, but no one is excluded. The Somerset Dementia Adviser Service is also open to all ages.</p>	<p>The Employment Support Service provides one to one support to people with early onset dementia who are in receipt of secondary care and in need of support to maintain or find employment. All of the factors (acute hospital/outpatient, gp/primary care, mental health provider, other commissioned support provider and voluntary sector) would be considered as part of a person centred approach.</p>
<p>Swindon Completed by Penny Mamo, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>Forget-Me-Not Service</p> <p>Forget-Me-not is based at Whitbourne House in Park South and part of AWP provision. It provides a "therapeutic day service for people with early onset dementia, families and carers". Most people are in their 50s and 60's although there are some younger and it does a whole range of activities which build on what people can do and are more attractive for the younger age group (e.g. arts and crafts, cooking, walking, trips out, sailing, pub lunches). Referrals to the service are via the GP to the Department of Old Age Psychiatry at the Victoria Centre.</p>	
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>We have a specific band 6 young onset dementia nurse in a ½ time role. That individual offers support and advice to the patient / family and engages them with various service provisions and provides a support group for carers of people who have FTD. They are also a non-medical prescriber which also forms as a useful intervention in that role.</p> <p>There is also access to more generalised dementia nurses / dementia advisors / managing memory services providing education services to the person with dementia / carer (provided to all irrespective of age).</p>	<p>Specifically focussed support for people with Young Onset Dementia is very limited and needs more attention through relevant sources / funding.</p> <p>A group was previously commissioned called 'Good to go' through the Alzheimer's Society.</p>
<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>Dementia Wellbeing Service: Specialist post-diagnostic support Younger People with Dementia Social Support Group Link with Vocational Service (return to work, maintain employment, entitled rights under the disability act, support for carers of people with dementia who are working) LIFT psychology service</p> <p>Memory Cafes</p>	<p>AgeUK (55+) Link Age (activities for the over 55's) Volunteer Bureau</p> <p>Care Direct? Brunelcare?</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>Not known – we offer Voluntary Sector support to those accessing Memory Clinic Support group</p>	

<p>North Somerset Memory Service Completed by Kay Stokes, Manager</p>	<p>We currently do not have in place formal post diagnostic support following a diagnostic appointment but do provide this on an adhoc basis reflecting the individuals need i.e. 1 – 1 support or family support from a therapeutic basis or more practical advice, support and signposting.</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (<i>OPMH</i>) Functional Community Team (Plym Locality)</p>	<p>Referral to Adult Social Care Memory Service follow-up by nurses Alzheimer's Society referral Referral to Plymouth Guild/HUB Other voluntary sector services as required</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Support is generally for all ages as we do not have many under 65 patients with dementia.</p> <p>Dementia support workers. Carers Centre Memory cafes etc Carers support groups. Carers' courses at RICE. CST groups – for younger people but would include people up to 70 PCLS and CITT</p>
<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>No specific support for young onset dementia, more integrated. Most support is provided through GPs dependant on post code of patient and what services are available. No HD nurse but general neurology nurses is accessible if appropriate.</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Not sure as our service does not diagnose dementia</p>

Is your service aware of the local availability of the following care options specifically for people with young onset dementia? If so, do you have a role in advising patients or their carers and facilitating access to the available options?

- Respite care
- Long term residential care particularly if the patient has behaviours which challenge

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service, Liskeard</p>	<p>In Cornwall we do not have any respite or long term residential facilities for people with a young onset dementia and therefore specialist, individualised packages need to be negotiated for each patient when the need arises.</p>
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	<p>Respite care – adult placement scheme in place (ageless).</p>
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>There is a dire shortage of any respite care for all patients with dementia and this would apply equally to those with YOD and this may even compound the situation.</p> <p>Finding long term residential care for people with YOD and challenging behaviour is difficult owing to a small bed base in S Glos and the fact that residential homes have become increasingly risk averse. Within AWP the services that would advise about residential care would be The residential Liaison service and the CITT.</p>
<p>Devon PT (except Plymouth) Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>Yes</p>
<p>Somerset Completed by a number of different people</p>	<p>Locally, Somerset County Council has a block contract with Specialised Residential Care provision at Longforth House for people with early onset dementia, plus floating housing support for people with dementia provided by Rethink.</p>
<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>Elaine Turner is best placed to answer this.</p> <p>At the Dementia Steering group there have been discussions about the availability of suitable provision for people with early onset who are more physically fit than older people with dementia.</p> <p>We are also looking at training for care homes on supporting people with challenging behaviour via the Wiltshire Care Skills Partnership.</p>

<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>This is very limited and normally involves advocating strongly for the patients and families so that they can have access to local health and social care teams to have a care needs assessment, and then look for availability of specific provisions and funding for this.</p> <p>Often we look at resources through LD services, adult placements through Social services, and in certain situations Out of county (extremely costly) placements have been utilised through the private healthcare system such as Priory group. Specific resources for patients with YOD are extremely limited and CHC/PIP and other benefits are often a challenge to acquire.</p>
<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>The Limes (YPWD day care ran by the Alzheimer's Society) which often requires a referral via Social Services re: funding</p> <p>There is currently a lack of specific respite care and residential / nursing care for YPWD within the Bristol locality.</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society, Wilts</p>	<p>Yes our role is to signpost and offer information as well as group services. Dementia Support Workers provide further support to the person with dementia and their carer(s).</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (OPMH) Functional Community Team (Plym Locality)</p>	<p>No specific facilities identified</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>We would liaise with and refer to the mental health team and dementia support workers regarding this.</p>
<p>Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Tend to refer back to GP as difficult to know what is available.</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>Some knowledge of the potential options</p>

How do you audit the effectiveness of all the things you are doing?

- If you gather patient and carer feedback which questionnaire/tool do you use?
- What data is contractually required by the service commissioner?
- Are you happy with the service you provide to people with young onset dementia?

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service, Liskeard</p>	<p>We gather patient and carer feedback via Meridian surveys and also Patient Advice and Liaison Service (PALS). I am unaware of what data is contractually required by our commissioners</p>	
<p>Cornwall Completed by Kate Mitchell, Kernow CCG</p>	<p>Contracting, health fairs, FFT, interviews in acute hospitals, collating patient experience from community hospital, collecting data from CST, memory cafes.</p> <p>Warwick – Edinburgh Mental Well-being Scale (WEMWBS) is used to gather feedback.</p>	<p>Meridian satisfaction questionnaires used contractually by service commissioner, but too many to list.</p> <p>Not happy with service provided for young onset dementia, it is not targeted or specific to needs, is ad hoc and not comprehensive or tailored to younger people's needs.</p>
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>We facilitate the completion of the Family and Friends Test for as many patients receiving services from us as possible. The feedback from this is compiled monthly within the locality and we are sent the results. Negative comments are investigated on a team basis and action is taken where to address issues.</p> <p>Most teams within the Trust complete 2 audits on a monthly basis. These include a Records Management audit and a further audit based on CQC standards (the latter is currently suspended pending an update to reflect the CQC's new standards arranged under 5 domains). This including other performance data and is reported back to the CCG on a monthly basis.</p> <p>All post diagnostic Groups are evaluated when they conclude. The comments made are considered and adjustments made as appropriate.</p>	<p>The feedback we have received is that there is a need for normalized activity for younger people who are no longer employed but whose partners are still working. This group are not asking for formalized Day care but activities could include volunteering, 'walk and talk' groups, activities that cater for physically able people in a supportive way.</p> <p>We endeavour within our current resources to provide age appropriate, quality assessments and post diagnostic support to all our service users. In the past two and a half years we have been successful at maximizing our resources and deploying these very efficiently by developing a Primary Memory service which operates in collaboration with our colleagues in Primary care and sits alongside our Secondary service. This has enabled us to significantly increase our capacity to carry out assessments, review service users who need specialist input and deliver appropriate post diagnostic support to all service users in the Secondary as required. We believe that we deliver a quality and sustainable service.</p>

<p>Devon PT Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>No separate mechanism for gathering feedback from young onset cases. We have considered the merits of a young onset service within the Trust (led by Dr McCollum) and concluded this would not be cost effective.</p>	
<p>The Mede and Seaward House, a day care facility in Devon Completed by Sallie Rutledge, The Mede and Seaward House Holiday support and day care for people with dementia and their carer</p>	<p>I am now running 2 properties and a third opening in June. I have holiday support for people with dementia and their carer. I find I do have young couples coming for respite and return several times I also now run 3 activity groups. 2 of the days are based in the house. 1 day is for the more active client and we go out and about. It is 10-4 so gives the carer a good break. I am looking to open a respite only property next door to these 2 properties. This will be for the person with dementia only and they will have 24 hour care. This is will be total respite for carers.</p>	<p>My frustration is getting people to hear about what I offer. I have tendered for DCC day services but this is a long process and I still have not heard from them. The DCC are looking for respite beds but again lots of hoops to get through. Very frustrating!</p>
<p>Somerset Completed by a number of different people</p>	<p>A local questionnaire is used to gather feedback for the Somerset Dementia Adviser Service. Friends and Family survey is used to gather patient and carer feedback. Honos Cluster data is contractually required by the service commissioner. Somerset is happy with the service provided to people with young onset dementia, given the resources available although there is always room for improvement.</p>	
<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>Sheila Baxter / AWP are best placed to reply to this.</p>	
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>We have a limited service provision for people with YOD. The service we do provide is of a high standard through general feedback. We utilise generic Managing Memory feedback forms, as well as the Trust friends and family feedback. We have a 4 week diagnosis to care plan target for all dementias which is set as a key performance indicator (KPI).</p>	<p>We feel that we need additional resources to provide services to those people and their families living with a Young Onset Dementia and our current resources are not adequate to meet the need.</p>

<p>Dementia Wellbeing Service, Bristol Completed by Sonya Pratt</p>	<p>Reviewing in outpatients clinic Informal reviewing and monitoring via YPWD social group Dementia Wellbeing Service: We would be really happy to become involved in an audit</p> <p>Happy with the service we currently provide (within our limited resources) and that we can refer onto the BRACE for more complex individuals (diagnostics only). You can always aspire to do better.</p> <p>Post diagnostic group and post clinic service user and carer questionnaire. We performance in house audits. Completed by Speciality Doctor.</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>Service Evaluations and Self Evaluations. This includes evaluation via stakeholders, commissioners of funding. As a charity we use PQASSO services standard to measure quality of care information and support.</p>
<p>Plymouth Community Healthcare Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (<i>OPMH</i>) Functional Community Team (Plym Locality)</p>	<p>Friends & Family Test</p>

RICE (Research Institute for the Care of Older People)
Bath & North East Somerset
Submitted by Laura Marsh
Commissioning Manager for Long Term Conditions
BaNES CCG

We audit the effectiveness of our service by designing good quality audit tools and using them to evaluate our service and strive for quality improvement where needed.

We run an annual Service User Audit, designed by ourselves, where we collect feedback from service users (patients and their carers) over a period of 6-8 weeks. On analysing their responses, we can gauge where the areas for quality improvement lie and raise these as actions to be followed up. These actions will then be re-audited six months later. The questionnaire is reviewed on an annual basis and updated where appropriate, ensuring that it always captures relevant data about our service.

Friends and Family test – this captures the age range of the patient if they are willing to give it.

What data is contractually required by the service commissioner?

Please see attached Reporting Template.

Are you happy with the service you provide to people with young onset dementia?

We aim to provide a service that is suitable for all ages. We are aware that some younger patients may be concerned that we have mainly older people attending the memory clinics. We do not see enough younger people to have a dedicated clinic so that all younger people could attend on the same day. We are recognised as having special expertise with people with semantic dementia (we have published many research papers on this group) and with PCA

A review of patients seen in 2013 showed

under 65	5%
65-69	6.2%
70-79	24.7%
80-89	50.5%
90 and over	13.2%

Royal United Hospital Bath - Neurology Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG	We don't have a formal service so do not audit.
Sirona Care & Health CIC- Bath & North East Somerset Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG	We do not diagnose or manage people with early onset dementia

What would you like to do better if you could?

How could the SCN help?

Would you support the development of a young onset dementia register (to facilitate involvement in research, help gather better data on prognosis)?

<p>Cornwall FT Completed by Allison O'Kelly, Clinical Lead East Locality Memory Service, Liskeard</p>	<p>A register of young on-set dementia people would be useful to look at trends such as sub-types, prognosis and engagement in research.</p> <p>Feedback from the FTD support group facilitator and what they see as important includes:</p> <ul style="list-style-type: none"> • 24 hour access to a crisis helpline • More information at diagnosis • Day care facilities: meaningful, purposeful, productive, fulfilling, age appropriate activities • Access to disabled parking/blue badges • Provision for children
<p>AWP South Glos Memory Team Completed by Kate Chisholm-Mitchell Service Manager – Later Life, South Glos Locality Acer Unit, Blackberry Hill Hospital, Bristol</p>	<p>Yes we would support the development of a Memory register for people with YOD.</p> <p>We would like to provide further tailor made activities for people with YOD in collaboration with other stakeholders in S .Glos. These activities should include a combination of social and physical activities such as age appropriate dances, cycling, cinema clubs, pub visits and so on. In order for people to access these activities and ensure that they are appropriate for the individuals participating, it would be helpful to have a 'volunteer buddy' system in operation ; this should be compose of skilled facilitators and would have small costs associated related to start up and transport costs.</p>
<p>Devon PT Completed by Emma Geach Business Administration Coordinator Older Peoples Mental Health (OPMH) Directorate, and Chris Whitehead, DPT</p>	<p>A YOD register is a good idea.</p>
<p>Swindon Completed by Penny Marno, Public Health Specialty Registrar, Swindon Borough Council</p>	<p>More understanding on prevention for early onset dementia so we can target appropriate public health campaigns. Best practice for support for people with early onset dementia and carers – I have a MPH student doing a systematic review on this as part of her dissertation but learning across the South West would also be useful.</p>
<p>Gloucestershire Completed by Rose McDowall, Team Manager, Managing Memory 2gether</p>	<p>We would like to be able to develop our service further to provide a specialist service countrywide.</p> <p>It is essential that we have a young onset dementia register for the reasons suggested and because how can we identify the need otherwise. We would like to provide a specific service provision for this care group on a much wider basis, provide specific patient/carers groups.</p>

<p>Dementia Wellbeing Service, Bristol</p> <p>Completed by Sonya Pratt</p>	<p>Assist in the development of suitable respite and long term care for YPWD and their families.</p> <p>We would support the development of a YPWD register.</p> <p>If the SCN could identify areas of research, we could approach suitable individuals who have consented to participate in research.</p>
<p>Completed by Marco van-Tintelen, Services Manager BANES, Swindon, Alzheimer's Society</p>	<p>Offer more specific services to people with EOD including immediate post diagnosis support and specialist groups. We would like more communication and collaboration between services. SCN could help with funding.</p>
<p>Plymouth Community Healthcare</p> <p>Completed by Mandy Rolfe, Modern Matron Older People's Mental Health (OPMH) Functional Community Team (Plym Locality)</p>	<p>Difficult to capture data through electronic systems</p> <p>A young onset dementia register would be useful</p>
<p>RICE (Research Institute for the Care of Older People) Bath & North East Somerset</p> <p>Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>We are not aware of much that is available in Banes specifically for under 65s but would refer to the Dementia support workers and the mental health team who will be up to date on what is available. Patients and carers have told us in the past that they are interested in doing physical activities as they are often physically very able.</p> <p>We rarely investigate possible genetic risk factors in this group where it may be more relevant than in late-onset dementia and this might be an area to develop further</p> <p>We would be interested in a register</p>
<p>Royal United Hospital Bath - Neurology</p> <p>Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>At the RUH it would be difficult to provide a dementia service with our current capacity and also lack of neuropsychology. I tend to refer on to a formal memory service elsewhere if the patients are interested in research.</p>
<p>Sirona Care & Health CIC- Bath & North East Somerset</p> <p>Submitted by Laura Marsh Commissioning Manager for Long Term Conditions BaNES CCG</p>	<p>N/A</p>