Does Dementia matter?

"High Quality Care for All, Now and for Future Generations"
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What does the Data Tell us?
Dementia Diagnosis – North Aggregate position

Estimated number of people still to be diagnosed (Jun)

50,809

CCGs range of values
- Standard
- NORTH OF ENGLAND
- MIDLANDS AND EAST OF ENGLAND
- LONDON
- SOUTH OF ENGLAND
Yorkshire and the Humber Dementia Diagnosis Rates by CCG:
65+ Years Age Group

% diagnosis (actual v. expected prevalence)

Airedale, Wharfedale and Craven: 73.7% (Aug-15), 75.2% (Sep-15)
Barnsley: 75.9% (Aug-15), 74.2% (Sep-15)
Bradford City: 84.9% (Aug-15), 85.3% (Sep-15)
Calderdale: 72.8% (Aug-15), 72.7% (Sep-15)
Doncaster: 59.4% (Aug-15), 61.7% (Sep-15)
East Riding of Yorkshire: 58.4% (Aug-15), 65.6% (Sep-15)
Greater Huddersfield and Walsley: 62.6% (Aug-15), 65.3% (Sep-15)
Hull: 59.0% (Aug-15), 60.1% (Sep-15)
Hull and East Riding: 85.8% (Aug-15), 85.3% (Sep-15)
Hull, York and North East Lincolnshire: 74.4% (Aug-15), 72.1% (Sep-15)
Leeds North: 73.4% (Aug-15), 72.4% (Sep-15)
Leeds South and East: 71.4% (Aug-15), 71.4% (Sep-15)
Leeds West: 74.5% (Aug-15), 74.5% (Sep-15)
North East Lincolnshire: 67.5% (Aug-15), 67.5% (Sep-15)
North Lincolnshire: 69.9% (Aug-15), 69.9% (Sep-15)
Rotherham: 74.5% (Aug-15), 74.5% (Sep-15)
Scarborough and Ryedale: 63.6% (Aug-15), 63.6% (Sep-15)
Sheffield: 80.4% (Aug-15), 80.4% (Sep-15)
Vale of York: 67.5% (Aug-15), 67.5% (Sep-15)
Wakefield: 67.5% (Aug-15), 67.5% (Sep-15)

National Ambition (66.7%) and Y&H Rate (71.0%) are shown as horizontal lines.

Bar charts for each area showing the percentage of diagnoses compared to expected prevalence.
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</thead>
<tbody>
<tr>
<td>Dementia: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>0.7</td>
<td>0.8*</td>
<td>1.1</td>
<td>0.9</td>
<td>1.0</td>
<td>0.8</td>
<td>0.7</td>
<td>0.6</td>
<td>0.8</td>
<td>0.9</td>
<td>1.1</td>
<td>0.8</td>
<td>0.7</td>
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<tr>
<td>Dementia: Recorded prevalence (aged 65+)</td>
<td>Sept 2015</td>
<td>4.27</td>
<td>4.45*</td>
<td>4.72</td>
<td>4.82</td>
<td>4.59</td>
<td>4.53</td>
<td>3.98</td>
<td>4.43</td>
<td>4.00</td>
<td>5.09</td>
<td>4.26</td>
<td>4.00</td>
<td>4.78</td>
<td>4.93</td>
<td>4.51</td>
<td>4.85</td>
<td></td>
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<tr>
<td>Smoking: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>18.4</td>
<td>20.2</td>
<td>17.2</td>
<td>22.0</td>
<td>21.9</td>
<td>23.2</td>
<td>21.0</td>
<td>21.8</td>
<td>18.5</td>
<td>15.5</td>
<td>25.9</td>
<td>17.3</td>
<td>24.4</td>
<td>21.5</td>
<td>21.0</td>
<td>19.2</td>
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<tr>
<td>Hypertension: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>13.8</td>
<td>14.2</td>
<td>14.9</td>
<td>15.7</td>
<td>8.6</td>
<td>13.2</td>
<td>15.3</td>
<td>15.2</td>
<td>16.9</td>
<td>13.0</td>
<td>16.2</td>
<td>14.6</td>
<td>13.3</td>
<td>13.0</td>
<td>13.0</td>
<td>14.6</td>
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<tr>
<td>DEM003: Blood tests recorded (den.incl excl.)</td>
<td>2014/15</td>
<td>74.7</td>
<td>72.5*</td>
<td>75.4</td>
<td>65.8</td>
<td>57.3</td>
<td>70.6</td>
<td>70.5</td>
<td>92.2</td>
<td>77.3</td>
<td>83.3</td>
<td>74.9</td>
<td>55.5</td>
<td>75.8</td>
<td>71.5</td>
<td>62.0</td>
<td>85.5</td>
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<tr>
<td>DEM002: Dementia care has been reviewed last 12 months (den.incl excl.)</td>
<td>2014/15</td>
<td>77.0</td>
<td>78.0*</td>
<td>77.8</td>
<td>76.7</td>
<td>72.4</td>
<td>81.0</td>
<td>77.4</td>
<td>75.2</td>
<td>73.0</td>
<td>79.7</td>
<td>80.5</td>
<td>71.3</td>
<td>81.3</td>
<td>75.5</td>
<td>85.8</td>
<td>76.9</td>
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<tr>
<td>Dementia: Ratio of inpatient service use to recorded diagnoses</td>
<td>2014/15</td>
<td>54.8</td>
<td>52.4</td>
<td>47.9</td>
<td>55.8</td>
<td>48.0</td>
<td>52.6</td>
<td>51.4</td>
<td>60.4</td>
<td>47.8</td>
<td>45.0</td>
<td>43.0</td>
<td>40.2</td>
<td>71.1</td>
<td>49.1</td>
<td>55.9</td>
<td>56.7</td>
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<tr>
<td>Dementia: DSR of emergency admissions (aged 65+)</td>
<td>2014/15</td>
<td>5060</td>
<td>3442</td>
<td>3079</td>
<td>4235</td>
<td>6046</td>
<td>3779</td>
<td>3726</td>
<td>3926</td>
<td>2757</td>
<td>3137</td>
<td>2562</td>
<td>2466</td>
<td>5185</td>
<td>3135</td>
<td>4223</td>
<td>3855</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Directly Age Standardised Rate of Mortality: People with dementia aged 65+</td>
<td>2014</td>
<td>752</td>
<td>787</td>
<td>874</td>
<td>593</td>
<td>1617</td>
<td>684</td>
<td>734</td>
<td>734</td>
<td>636</td>
<td>783</td>
<td>564</td>
<td>794</td>
<td>936</td>
<td>689</td>
<td>464</td>
<td>819</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths in Usual Place of Residence: People with dementia aged 65+</td>
<td>2014</td>
<td>67.5</td>
<td>67.1</td>
<td>60.1</td>
<td>72.3</td>
<td>67.8</td>
<td>72.3</td>
<td>63.5</td>
<td>60.6</td>
<td>73.2</td>
<td>67.2</td>
<td>70.1</td>
<td>73.8</td>
<td>58.3</td>
<td>61.8</td>
<td>62.0</td>
<td>66.7</td>
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</tbody>
</table>

* Data marked with an asterisk are an estimate.
Why is a diagnosis important?
Patients and their Carers want it!

“It was a huge relief...right thank goodness now we’ve got a diagnosis, now I know what I’m dealing with and I’ll cope with it”

“It’s an illness, it’s a terminal illness as well you know, nobody gets better from it, and it isn’t treated like that with the NHS is it, unfortunately...if it was cancer it would be different, you know”

“Absolutely instead of being really really aggravated you become empathic on diagnosis”

Source: Dementia in Leeds Evaluation Project, 2013
Transforming ‘toxic uncertainty’ into ‘empowered understanding’
Right to Know Campaign

• Imagine feeling ill but being told your new symptoms and behaviour were just a natural part of ageing. Imagine having a condition but no treatment, information, or support to help you manage it. Imagine if your doctor knew about your condition but chose not to tell you, as they thought nothing could be done to help.
• For many people with dementia, this is the reality. Denied a diagnosis, denied treatment, and denied the chance to plan for the future while still able to do so.
• At Alzheimer's Society we think this is wrong. We think everyone with dementia has a Right to Know. A Right to Know about their condition in order to tackle it head on. A Right to Know about the information and advice available to them. A right to be fully supported after their diagnosis. This is not a lot to ask, and only what people deserve.
Why is Dementia important to the CCG?
Why is it important for the NHS and LA

• We spend £23 Billion a year as a society and we can spend this money more effectively rather than on expensive crisis interventions
  - Crisis presentations
  - Care Home Admission (or delay them)
  - Reduce Emergency Admissions and readmissions to Hospital
  - Reduce hospital Length of Stay
• Spend the money saved on more meaningful support
2.1 People with dementia in hospital

People with dementia are substantial users of hospital care. In 2001 the National Service Framework for Older People found that older people (over 65 years of age) are the core patient group in acute hospitals, accounting for 60% of hospital bed days in the UK (Department of Health, 2001). Of this 60%, research found that up to 40% have dementia (Holmes and House, 2000), meaning that people with dementia over 65 years are using up to one quarter of hospital beds at any one time.

Recent research has suggested that the prevalence of dementia in the acute hospital population increases with age. Sampson et al. (2009) studied individuals aged over 70 with unplanned acute admission to a north London general hospital. They found that 42% of individuals aged over 70 (average age 83) had dementia. In individuals aged over 80 years 48% had dementia. Sampson et al. (2009) found that only 21% had received a diagnosis of dementia prior to the research.
2.1.1 Why are people with dementia in hospital?

The DEMHOS research found that the majority of people with dementia entered hospital from their own home (60%), although admission for people with dementia from a care home was also common (33%). This reflects the split in residential status estimated in Dementia UK (Alzheimer’s Society, 2007) with two thirds of people with dementia living in their own homes and one third living in care homes.

**In the DEMHOS research, the primary cause of admission for people with dementia was a physical health issue. 37 reasons were cited for entry to hospital, with the top five reasons (with the highest percentage of respondents) shown in Table 1.**
### Proportion of people with dementia admitted to hospital by primary diagnosis (the top five reasons with highest percentage of respondents)

<table>
<thead>
<tr>
<th>Reason for admission</th>
<th>Proportion of total number of carer respondents reporting reason for admission for the person with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Following a fall</td>
<td>14%</td>
</tr>
<tr>
<td>Broken/fractured hip or hip replacement</td>
<td>12%</td>
</tr>
<tr>
<td>Urine infection (including urinary tract infection)</td>
<td>9%</td>
</tr>
<tr>
<td>Chest infection</td>
<td>7%</td>
</tr>
<tr>
<td>Stroke/minor stroke</td>
<td>7%</td>
</tr>
</tbody>
</table>

These results are supported by the research literature. For example, a Birmingham-based study (Natalwala et al., 2008) explored the lack of evidence to explain why people with dementia are admitted to a general hospital. The results found that more people with dementia were admitted as emergency cases and that the proportion of patients admitted for dementia as their primary diagnosis was small. Primary diagnoses included syncope (loss of consciousness) and collapse, bronchopneumonia, urinary tract infection and dehydration. Sampson et al. (2009) found that 43% of admissions of people with dementia were for pneumonia and urinary tract infection.
2.2 Outcomes of being in hospital

Research literature has found that poorer outcomes result from a person with dementia being admitted to a general hospital ward for a medical procedure than a person without dementia being admitted for the same procedure.

For example, Holmes and House (2000) found that presence of dementia had an effect on several important outcomes when elderly people were admitted to hospital with a hip fracture compared to those without dementia. Including increased length of stay, decreased chance of survival after six months, an increased chance of discharge to a residential or nursing home, and an increased likelihood of physical dependence (and increased physical dependence was significantly related to residence in institutional care).

Many of these reported poor outcomes are supported by the DEMHOS research findings.
2.2.2 Increased likelihood of discharge to residential care setting

The DEMHOS research shows that there is an increased likelihood of being discharged to a care home following a stay in hospital. Table 5 gives an overall breakdown of results and shows that the likelihood of entering a care home after a stay in hospital is very high. The data shows that over a third of people who enter hospital from their own home go into a care home. 60% of people with dementia in the DEMHOS research entered hospital from their own home and this was reduced to 36% returning to their own home.

Table 5
Person with dementia’s place of residence before and after entering hospital as reported by carer respondent

<table>
<thead>
<tr>
<th>Place of residence response options</th>
<th>Proportion of carer respondents giving response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Place of residence before hospital</td>
</tr>
<tr>
<td>Care home</td>
<td>33%</td>
</tr>
<tr>
<td>Own home</td>
<td>60%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
<tr>
<td>Not applicable</td>
<td>–</td>
</tr>
</tbody>
</table>

* This 9% can be explained by situations where the person with dementia has not yet been discharged from hospital or where the person with dementia died whilst in hospital.
2.3.1 Estimated savings by reducing the length of stay for people with dementia by one week

The data comparison between HES data and the DEMHOS research shows clearly that people with dementia are routinely staying longer than other people who go into hospital for the same procedures. This is supported by the views of nurse managers and carers in the DEMHOS research. The data also shows that a significant number of people with dementia are staying in hospital for many weeks longer than other people who go in for similar procedures.

Alzheimer’s Society believes that as a starting point it would be reasonable for hospitals to work towards supporting people with dementia to leave hospital one week sooner than they currently do. Based on the understanding that up to a quarter of people in hospital have dementia (25%) (see section 2.1), Table 13 shows estimated savings which could be made in one year from only four HES data codes.
Estimated savings which could be made by reducing the length of stay of people with dementia in hospital by one week

<table>
<thead>
<tr>
<th>Diagnosis/operation</th>
<th>HES total number of admitted cases in 07/08</th>
<th>Estimated number of admitted cases with dementia (based on 25% of the total number of people admitted being people with dementia)</th>
<th>Excess day tariff (08/09)</th>
<th>Estimated savings (England wide) in one year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fracture of femur</td>
<td>74,111</td>
<td>18,500</td>
<td>£216</td>
<td>£28 million</td>
</tr>
<tr>
<td>Total prosthetic replacement of hip joint using cement</td>
<td>32,836</td>
<td>8,200</td>
<td>£248</td>
<td>£14 million</td>
</tr>
<tr>
<td>Urinary tract infection, site not specified</td>
<td>123,273</td>
<td>30,800</td>
<td>£176</td>
<td>£38 million</td>
</tr>
<tr>
<td>Transitory Ischemic Attack (TIA)</td>
<td>19,163</td>
<td>4,800</td>
<td>£178</td>
<td>£6 million</td>
</tr>
</tbody>
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Total Estimated savings £86 million Nationally on just 4 conditions
Also important as part of CCG monitoring

- STP
- CCG Improvement and Assessment Framework
  - Dementia Diagnosis Rates
  - % Face to Face Care Planning Reviews
Sustainability and Transformation Plan for Dementia

Outcomes and Impact
Achieving/maintaining diagnosis rate
Accessing post diagnostic support and care planning
Maintaining independence in the community
Avoiding unnecessary hospital admission and readmission
Supporting prevention
Encouraging dementia friendly communities
Accessing Cognitive Stimulation Therapy
Enabling appropriate antipsychotic drug prescribing
Facilitating Advance Care Planning

Family and carers

Person with dementia

Community

Dying well

Living well

Supporting well

Diagnosing well

Preventing well

Benchmarking

Identifying gaps

Implementing

Learning from others

Selective investment

www.england.nhs.uk
What are the barriers to getting a diagnosis?
GPs are one of the biggest barriers!

• NAO found that fewer than 2/3 of GPs felt it was important to actively look for early symptoms.
• GPs who completed the knowledge test had an average score of 47%
• GP attitudes to Dementia were contributing to the delays in diagnosis-there was an attitude of ‘what difference will it make’
• Only 31% felt they had enough knowledge to manage the disease.
## Incentives for General Practice

<table>
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<tr>
<th>PRACTICE 1 – 10,000 patients</th>
<th>PRACTICE 2 – 10,000 patients</th>
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<tbody>
<tr>
<td><strong>Low prevalence, high point achievement</strong></td>
<td><strong>High prevalence, less point achievement</strong></td>
</tr>
<tr>
<td>Average £ per point = £227.02</td>
<td>Average £ per point = £227.02</td>
</tr>
<tr>
<td>Dementia National Prevalence = 0.5%</td>
<td>Dementia National Prevalence = 0.5%</td>
</tr>
<tr>
<td>Practice Prevalence = 0.3%</td>
<td>Practice prevalence = 0.7%</td>
</tr>
<tr>
<td>Dementia point value drops to £136.21</td>
<td>Dementia point value increases to £317.83</td>
</tr>
<tr>
<td>Dementia points achieved = 26 (maximum)</td>
<td>Dementia points achieved = 20</td>
</tr>
<tr>
<td><strong>Total income for dementia = £3,541.46</strong></td>
<td><strong>Total income for dementia = £6,356.60</strong></td>
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<table>
<thead>
<tr>
<th>Income increase by adding patients to the register</th>
<th>Amount</th>
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<tr>
<td>10 patients</td>
<td>£1,180.50</td>
</tr>
<tr>
<td>20 patients</td>
<td>£2,361.00</td>
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<tr>
<td>50 patients</td>
<td>£5,902.51</td>
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</table>
Why does a diagnosis make a difference?
## ACCESS TO SERVICES & SUPPORT!

<table>
<thead>
<tr>
<th>NHS</th>
<th>Social Care</th>
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<tbody>
<tr>
<td>Care Planning to reduce admission</td>
<td>Day Care</td>
</tr>
<tr>
<td>Advance Care Planning/DNA CPR</td>
<td>Respite</td>
</tr>
<tr>
<td>End of Life Care</td>
<td>Home Care</td>
</tr>
<tr>
<td>STOPP Medication</td>
<td>Equipment</td>
</tr>
<tr>
<td>Secondary Prevention-vascular</td>
<td>Assistive Technology</td>
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<tr>
<td>CPN support</td>
<td>Work Advise</td>
</tr>
<tr>
<td>Research</td>
<td>Driving Support</td>
</tr>
<tr>
<td>Hospital Liaison</td>
<td>Benefits</td>
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<tr>
<td>Hospital schemes such as ‘Forget me not’</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Third Sector</th>
<th>Carers</th>
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</thead>
<tbody>
<tr>
<td>Alzheimer's Society</td>
<td>LA Carer assessments</td>
</tr>
<tr>
<td>Age Concern</td>
<td>Peer support</td>
</tr>
<tr>
<td>Carers Organisations</td>
<td>Care Health check and flu imms</td>
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<tr>
<td></td>
<td>Benefits (Carers allowance)</td>
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<tr>
<td></td>
<td>Respite</td>
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</tbody>
</table>
What are the national recommendations?
# NHS England Transformation Framework – The Well Pathway for Dementia

## Preventing Well
- Risk of people developing dementia is minimised.

### Standards:
- Prevention
- Risk Reduction
- Health Information
- Supporting research

## Diagnosing Well
- Timely accurate diagnosis, care plan, and review within first year.
- “I was given information about reducing my personal risk of getting dementia.”

### Standards:
- Diagnosis
- Memory Assessment
- Concerns Discussed
- Investigation
- Provide Information
- Integrated & Advanced Care Planning

## Supporting Well
- Access to safe high quality health & social care for people with dementia and carers.
- “I was diagnosed in a timely way.”
- “I am able to make decisions and know what to do to help myself and who else can help.”

### Standards:
- Choice
- Liaison
- Advocates
- Housing
- Hospital Treatments
- Technology
- Health & Social Services
- Hard to Reach Groups

## Living Well
- People with dementia can live normally in safe and accepting communities.
- “I am treated with dignity & respect.”
- “I get treatment and support, which are best for my dementia and my life.”

### Standards:
- Integrated Services
- Supporting Carers
- Carers Respite
- Co-ordinated Care
- Promote independence
- Relationships
- Safe Communities

## Dying Well
- People living with dementia die with dignity in the place of their choosing.
- “I know that those around me and looking after me are supported.”
- “I feel included as part of society.”

### Standards:
- Palliative care and pain
- End of Life
- Preferred Place of Death

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**References:**
1. NICE Guideline.
4. NICE Pathway.
6. BPSD – Behavioural and Psychological Symptoms of Dementia.

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

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

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

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

### Monitoring Well
- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set ‘profiled’ ambitions for each.
- Use the Intensive Support Team to provide ‘deep-dive’ support and assistance for Commissioners to reduce variance and improve transformation.
What makes a difference?
What makes a difference?

• CCG/Governing Body Ownership and support
• Dementia Strategy Groups
• Strong clinical Leadership with support
• Effective Relationships with Providers
• Education of GPs and Primary Care
• Work with Care Homes
• Clear Pathways to diagnosis & Support
• Dementia part of other work steams-Self care etc
• Coding Audits
• High uptake of initiatives
Thank You!

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- nicola.phillis@nhs.net
- Penny.kirk@nhs.net