Training and education programmes on
dementia and end of life care in the context of
the West Midlands Clinical Pathway Group
(Darzi) Dementia Pathway

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Please see Appendices 2 and 4 for a comprehensive list of providers consulted during the project.
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Executive Summary

This project was commissioned by the West Midlands Strategic Health Authority (SHA) and undertaken by the Association for Dementia Studies, University of Worcester. The aims were to identify end of life dementia training and education available within the West Midlands and to identify where the gaps in the training were when compared to the West Midlands Clinical Pathway Group (CPG) (Darzi) Dementia Pathway.

Core context

There is a predicted increase in both the prevalence and absolute numbers of people with dementia over the next 50 years, meaning that dementia will present a challenge for services as the population ages. Dementia is now recognized as a progressive terminal illness. Furthermore, with advanced disease surveillance and increased longevity, the number of people with a co-morbid life-limiting illness, other than dementia, is expected to increase as better understanding of risk factors, particularly related to vascular disease, emerge within the research. People with dementia over 65 years of age are using up to one quarter of hospital beds at any one time and hospitalised patients over age 85 with cognitive impairment have an increased mortality rate.

A palliative care approach is proposed to be of specific benefit to patients with dementia because of its emphasis on supportive care (including support for family), quality of life, aggressive symptom control, attention to formulating goals of care that guide medical decision making, creation of a comfortable end-of-life experience, and bereavement services. Despite this, patients dying with dementia are often not given access to palliative care services and die with inadequate assessment and management of pain and other symptoms, and family members are poorly supported during bereavement.

There is an urgent need to improve palliative care provision for people with dementia and their families and to allocate appropriate resources and training for people who provide care for people with dementia at the end of life. The National Dementia Strategy (DH, 2009) recommends that all staff working with
older people in the health, social care and voluntary sectors have access to dementia care training and skill development that is consistent with their roles and responsibilities. Improved knowledge and working in collaboration with people with dementia and their carers can allow people with dementia to be cared for and supported during dying and bereavement in all care environments and also in their own homes.

Project design
This project was undertaken in three main phases. These were: 1) determining areas related to end of life dementia care; 2) identifying training courses actually available in the West Midlands; 3) mapping the available training courses against the main stages in the West Midlands CPG (Darzi) Dementia Pathway and identifying gaps in these services. Phase 2 formed the main part of the project due to the number of organisations involved. The search for training courses took place between September and November 2010. Courses developed since November 2010 are not included in this work.

Findings

Education programmes and resources that are already being used across the West Midlands

- Due to the number and type of providers considered, there is a degree of inconsistency between courses in terms of the contents, duration and the level to which topics are studied.

No areas of the West Midlands CPG (Darzi) Dementia Pathway were particularly well covered by the courses.

- The focus of the dementia specific courses was on awareness of dementia, especially the different types of dementia, and caring for people with dementia with over half of the courses being called ‘Dementia Awareness’ or ‘Dementia Care’.

- Diagnosis was the second highest area being covered by 22% of dementia specific courses, although the focus was mainly on signs and symptoms rather than how to diagnose dementia.

- Education on symptom and pain management covered both medical and non-medical options, but medication was the main focus for the dementia specific courses.
• Prevention was not mentioned in any course description, but it is suggested that dementia specific courses assume that the person already has dementia, so prevention is not deemed relevant.

• The end of life phase (end of life care/palliative care and bereavement) was only covered by 15% of dementia specific courses, with no course descriptions mentioning bereavement at all.

• Coverage of the end of life phase was a lot higher among the dementia related courses, with 42% of courses covering end of life/palliative care, and 12% of courses covering bereavement.

• Advance Care Planning was not covered widely by dementia related courses at 13%, but was better than in the dementia specific courses where it was only covered by 6% of the courses.

• The majority of palliative care courses were run by hospices. This is their field of work so these areas could be seen as specialist or less of a priority in wider training circles.

None of the more specific ‘Recommended topics’ identified during this work were particularly well covered by the courses.

• ‘Types of dementia’ was covered by over 50% of the dementia specific courses which, due to the number of dementia awareness courses mentioned previously, was not unexpected.

• Person centred care was the only other fairly strong topic, covered by 45% of dementia specific courses.

• Involving the person with dementia in their care and the decision making process were both very poorly covered by dementia specific courses.

• Challenging behaviour, communicating with patients and medication/treatment/interventions were better covered by dementia specific courses than many other topics, at 26%, 32% and 26% coverage respectively.

• Coverage of pain assessment on dementia specific courses was very low at just 5%.

• For dementia related courses, none of the individual topics was covered by more than 30% of the courses, with the topic spanning medication/treatment/interventions having the highest coverage at 27%.
• Dementia related courses generally provided better coverage of topics that are not specific to dementia but where dementia can be used as an example condition, e.g. Mental Capacity Act, communication with the patient and bereavement support, were all covered by 15% of courses.

• Overall, topics relating to communication or to the carer rather than the person with dementia had low coverage rates.

Working partnerships of multidisciplinary and multi-agency on dementia and end of life and key contacts in delivering education on dementia and end of life care

• There were generally strong links between Universities, PCTs and Hospices.

• Hospice links with other providers, from across the West Midlands were varied, in that some had very strong links with other providers whilst others had very tenuous links.

• The Colleges did not appear to have links to other providers and their courses were more generic and did not require educators with specialist skills in dementia or palliative care.

Where and to whom education is being delivered

• Courses are offered by a range of providers at various educational levels across the West Midlands, making them accessible to a variety of people including medical professionals, healthcare workers and carers.

• Coventry, Herefordshire and Warwickshire had low numbers of courses, but have good connections with other counties and so can benefit from their training provision.

• Staffordshire had a high number of courses, with the majority of those being provided by one hospice and one University, and similarly most of the non-hospice courses in Shropshire were run by one private provider.

• In general, Primary Care Trusts (PCTs) did not offer many dementia courses, but tended to get courses from other providers.

• Although dementia specific courses are offered at University module and degree level or as a college course with a recognised qualification, most
are standalone courses. Dementia related courses are more likely to be more formally taught modules or degrees, resulting in a qualification.

If and how the programmes are mapped against the West Midlands CPG (Darzi) Dementia Pathway

- None of the courses identified actually followed the West Midlands CPG (Darzi) Dementia Pathway

Gaps in the service of provision of education on dementia and end of life care

- Dementia prevention.
- Advance care planning and involving the patients in care and decision making following diagnosis.
- Bereavement, especially in dementia specific courses.
- The majority of palliative care courses that had a component related to dementia were run by hospices.
- Pain assessment as part of symptom/pain management.

Specific local needs based on demographic differences

- Birmingham has a higher Black and Minority Ethnic (BME) population therefore training and education would need to reflect the needs of this group.
- The more rural areas had a lower BME population but a higher life expectancy and the issue of accessing education and training programmes.

Recommendations

- Widen the scope of existing dementia courses to cover more parts of the West Midlands CPG (Darzi) Dementia Pathway.
- Include dementia in courses covering related areas, and monitor the National Vocational Qualification (NVQ) and Business and Technology Education Council (BTEC) transition to the Qualification and Framework (QCF) structure, which could more than double the number of dementia courses available in the West Midlands. These courses are a good source of dementia training and could help to address some of the training gaps
and areas for improvement. They are also an important qualification for care home staff, providing a key method for extending dementia training into care homes.

- Build on the base of existing courses and explore the range of options available for consolidating, enhancing and expanding courses to make dementia training and education courses more accessible and wide-ranging in terms of their content, delivery and provider location.

- Prevention could be covered by health promotion courses instead, and these courses were not necessarily identified in this work. Also, based on emerging research dementia prevention is closely linked to prevention of vascular disease, so future education in this area could form part of a wider framework of health risks.

Conclusion
Despite compelling evidence within the literature that there is a need to educate care staff about end of life and bereavement issues and needs for people with dementia, there is little occurring in the West Midlands. Overall, these results suggest that although no individual course covered all areas of the dementia pathway and both dementia specific and dementia related courses had limitations and were weaker in some areas, they are both important sources of dementia training. The dementia specific courses provide deeper knowledge of dementia and an introduction to a range of areas, while dementia related training provides a deeper knowledge of the areas and how they are relevant to dementia. The end of life phase was recognised as being an important part of the dementia journey, but one that not much is known about in relation to dementia. This matches the course analysis carried out for this work which found that although a good number of ‘Other relevant training’ courses address end of life issues, dementia-specific end of life training was an area requiring improvement.

Dementia training is a niche area, especially when compared to the number of courses on offer in the West Midlands. Existing dementia courses are regularly cancelled due to low numbers, and there is a good range of ‘Other relevant training’ courses available, therefore creating new courses to address training gaps may not necessarily be appropriate or cost effective.
Although many of the training gaps are improved by including additional courses such as the ‘Other relevant training’, none has been filled altogether. For this to happen, new courses would have to be commissioned to specifically address these areas, or existing courses would have to be adapted or updated to include them. Many providers do actually advertise that they can create bespoke or tailored courses on request to meet individual needs and requirements, so there is the potential for either option to be taken forward, especially with providers that already run similar courses.
Introduction

This project was based on the principles outlined in the West Midland Strategic Health Authority (SHA) report by the West Midlands Clinical Pathway Group (CPG) (Saad et al, 2008). The aims of this project were to identify end of life dementia training and education available within the West Midlands and to identify where the gaps in the training were when compared to the West Midlands CPG (Darzi) Dementia Pathway (Saad et al, 2008). Of particular interest for this work was education related to:

- Advanced care planning services;
- Decision making processes for end of life care at diagnosis and throughout the illness;
- Multidisciplinary and multi-agency working (in all sectors i.e. care homes, community, acute sector, specialist palliative care services) in relation to end of life care;
- The relevance of long term conditions/co-morbidities to end of life care.

It was also based on the dying trajectories of people with dementia which can be that the person:

- Reaches the end of their life with dementia but dies from another condition;
- Reaches the end of their life with a complex mix of dementia and co-morbidities which together lead to their death;
- Dies as a result of advanced/end-stage dementia.

It is recognised that similar work looking into the provision of dementia training in the West Midlands has been carried out previously (Tsaroucha et al, 2010), and there will be some overlap with that study. However, this project includes hospices in its list of providers and covers a wider range of courses, in that it has not just focused on courses specifically covering dementia. In addition to identifying dementia training courses, this work identifies courses that cover areas relevant to dementia care which could potentially be used as a starting point when addressing any training gaps related to end of life care, advance care planning and bereavement experiences in dementia. This work also
differentiates between different types of dementia training, considering courses that are specifically about dementia separately from courses where dementia is covered as part of a wider range of topics.

The main focus of the previous study, in terms of mapping, was on mapping skills and competencies against the West Midlands CPG (Darzi) Dementia Pathway to determine their importance, with less reporting on the actual contents of the courses. This project focuses more on mapping the content of courses themselves against the West Midlands CPG (Darzi) Dementia Pathway to determine potential training gaps. Although this work is mainly interested in end of life dementia care, all areas of dementia care were considered during the mapping process to see how well end of life care is covered in comparison to other areas.

**Background literature**

There is a predicted increase in both prevalence and absolute numbers of people with dementia over the next 50 years, and this is a matter of concern to policymakers and providers (Alzheimer’s Research Trust, 2010; DH, 2009; Knapp et al., 2007). Furthermore, with advanced disease surveillance and increased longevity, the numbers of people with a co-morbid life-limiting illness, other than dementia, is expected to increase as better understanding of risk factors, particularly related to vascular disease, emerge within the research (Kivipelto et al., 2001, 2005; Rusanen et al., 2010; Whitmer et al., 2005).

Dementia is now recognized as a progressive terminal illness (Addington-Hall, 2000; Birch and Draper, 2008; Brayne et al., 2006; DH, 2003; de Vries et al., 2003; Ghiotti, 2009; Goodman et al., 2010; Hughes et al., 2007; Lloyd-Williams and Payne, 2002; Mitchell et al., 2007; NCPC, 2006; Sampson et al., 2006a, 2006b; Sanders et al., 2009; Shuster, 2000; Treloar et al., 2009; van der Steen, 2010), and society is now compelled to consider how people with dementia will be cared for at the end of their lives. Patients dying with dementia have significant healthcare needs and in recent years it has been recognised that palliative care should be made available to everyone regardless of diagnosis (DH, 2003, 2005, 2008; NCPC 2005a, 2005b). Dementia patients are also at risk of over-treatment with
b Burdensome and possibly non beneficial interventions and under-treatment of symptoms (van der Steen, 2010).

People with dementia over 65 years of age are using up to one quarter of hospital beds at any one time (Alzheimer’s Society, 2009) and 42% of individuals aged over 70 years with unplanned admission to an acute hospital have dementia, rising to 48% in those aged over 80 years (Sampson et al, 2009). Hospitalised patients over age 85 with cognitive impairment have an increased mortality rate (increased risk of death within the hospital) in the first year after hospitalisation and cumulatively (Freedberg et al, 2008; Sampson et al, 2009). Twenty-four percent of acute medical admissions with severe cognitive impairment died during admission (Sampson et al, 2009).

A palliative care approach is proposed to be of specific benefit to patients with dementia because of its emphasis on supportive care (including support for family), quality of life, aggressive symptom control, attention to formulating goals of care that guide medical decision making, creation of a comfortable end-of-life experience, and bereavement services (Sampson et al, 2006a, 2006b; van der Steen, 2010). The prognosis for dementia may range from two to over 15 years with the end-stage of the illness lasting as long as two or even three years (Bekelman et al, 2005; Shuster, 2000). Despite this, patients dying with dementia are often still not given access to palliative care services and many still receive suboptimal end-of-life care (Addington-Hall, 1998; Birch and Draper, 2008; House of Commons Health Committee, 2005). Often they die with inadequate pain control, and without the benefits of hospice care (Frampton, 2003; Franks et al, 2000; Sachs et al, 2004). Also difficulties associated with diagnosing the terminal phase of the illness (prognostication); issues relating to communication; medical interventions; and the appropriateness of palliative care intervention have been identified (Birch and Draper, 2008).

Research in the USA has identified that only between 7% and 11% of hospice patients have a primary diagnosis of dementia (Mitchell et al, 2007). In the UK it is reported that less than 2% of people in the UK with dementia are in hospice care (McCarthy et al, 1997). However, a chart audit of a 28-bedded hospice found
that 9% of referrals received within a three month period were for people who had dementia, primarily as co-morbidity to another life limiting illness (Nowell and de Vries, in preparation).

The National Dementia Strategy (DH, 2009) aims to improve education and training, bring care closer to home, promote living well with dementia, improve choice and control and end of life care, as do the aims of the End of Life Care Strategy (DH, 2008). People with chronic illness, including dementia, are not routinely consulted on this area of care particularly regarding preferred place of death (Pemberton et al. 2003; Storey et al. 2003). The preferences of the people with life-limiting illnesses and their informal caregivers regarding place of care and death have been major themes in palliative care research. Research has shown that the majority of patients would prefer to die at home, but that few are able to achieve this (Higginson 2003; Higginson et al., 2003). Studies carried out into the relationship between stated preferences of the terminally ill and the actual place of death show that the proportion of those who actually die at home ranges from 28 to 47% in industrialised countries (Addington-Hall et al. 1991, Cantwell et al., 2000, Tiernan et al., 2002).

Consultation on preferred care during the course of a chronic life-limiting illness and at the end of life may reduce anxiety about death for people with dementia and their significant other(s). Research on interventions within the palliative care literature has shown that this may be achieved through early discussion and documentation of preferred priorities of care, at the end-of-life (Pemberton et al. 2003; Storey et al. 2003; Higginson and Sen-Gupta, 2004). However, even though palliative care for people with dementia and care at home are key National Health Service (NHS) priorities, services that set out specifically to support palliative care of dementia at home are virtually non-existent (Treloar et al., 2009).

Staff working in the field of palliative care place more emphasis on availability as a means of support. Availability is also important for families of dementia patients, but the need here can differ during different phases (Albinsson and Strang, 2003). Staff in palliative care pointed out the importance of supporting families when the patient dies and following them up after the death whereas
there is often inadequate follow-up of family members following the death of a person with dementia despite the fact that existential concerns related to death obviously are important for the families (Albinsson and Strang, 2003; Murphy et al, 1997). One reason for this could be that dementia staff do not feel comfortable discussing existential issues and death (Albinsson and Strang, 2002).

There are many challenges for staff when caring for persons with advanced dementia as perceived by key professional providers, and there is an identified need for improved knowledge and skills, and clearer policy (Chang et al, 2009; Johnson et al, 2009). There is an urgent need to improve palliative care provision and conduct more research in this field to assist in the allocation of appropriate resources and training for people who provide care for people with dementia at the end of life (Birch and Draper, 2008; Sachs et al, 2004; Sampson et al, 2006a, 2006b; van der Steen, 2010). Concerns include accurate assessment, especially of pain, owing to the inability of people with advanced dementia to communicate their symptoms; management of end-of-life symptoms; managing physical and behavioural symptoms; and communicating with family members (Chang et al, 2009; Johnson et al, 2009).

Staff need to receive relevant education and training beyond their generalist competencies particularly in communication; the use of advance care plans in the planning and documentation of end-of-life decisions; and developing systems to enhance communication between key providers i.e. the person with advanced dementia, the family and the multidisciplinary team (Johnson et al, 2009). Working in collaboration with people with dementia and their carers can allow people with dementia to die in their own homes and people who are allowed a choice about their place of death tend to have a better death, and the experience of their relatives has also been found to be more positive (Volicer et al, 2001, 2003; Lindsay et al, 2010).

The National Picture

Dementia has become high profile over recent years and it has been acknowledged that dementia will present a challenge for services as the population ages. The National Dementia Strategy (DH, 2009) highlights the need
to ensure that the workforce has the correct skills and competencies to deliver services that will inform individuals of the benefits of timely diagnosis, promote the prevention of dementia and support living well with dementia. Workforce development underpins the whole of the National Dementia Strategy and improving public and professional awareness and understanding of dementia is its first objective. It is also recommended that all staff working with older people in the health, social care and voluntary sectors have access to dementia care training and skill development that is consistent with their roles and responsibilities (NICE, 2007).

Dementia has generally suffered from poor levels of awareness and understanding, and has a stigma attached to it due to its connections with both old age and mental illness. In addition, as reported in (National Audit Office, 2007), many General Practitioners (GPs) do not feel confident making a diagnosis of dementia, and in cases where a diagnosis is actually made it is often late in the illness when there are limited opportunities for beneficial intervention. Removing the stigma of dementia and increasing awareness amongst the public and amongst GPs of the symptoms and the options available could therefore result in an earlier diagnosis, when interventions could still have beneficial effects for both the patient and their carers or family.

**The West Midlands Clinical Pathway Group (Darzi) Dementia Pathway**

The West Midlands CPG (Darzi) Dementia Pathway (Saad *et al*, 2008) was developed as there were no overarching services for dementia in the West Midlands. The main features of the pathway can be seen in Figure 1, and the vision of the pathway is to ensure that by 2012:

“all people with a suspected or confirmed diagnosis of Dementia will access an integrated, seamless, proactive and high quality locality based service that encompasses all the expertise to meet needs of the people with Dementia and those of their carers. The emphasis will be on personalisation and choice.” p5
Figure 1 - The West Midlands CPG (Darzi) Dementia Pathway

From Figure 1, the main points within the West Midlands CPG (Darzi) Dementia Pathway are identified as:

- Prevention
- Awareness
- Diagnosis
- Advance Care Planning
- Symptom & Pain Management
- Carer & Family Support
- End of Life & Palliative Care
- Bereavement

Project design and methodology

This project was undertaken in three main phases:

1. Determining which areas relating to dementia are frequently mentioned by dementia reports and literature as being potential areas for development or improvement. This could be due to their benefits for the patient, carer, professional, health service or finances. These were
considered as topics that were ‘recommended’ as being covered by training courses.

2. Finding out what training and education courses are actually available in the West Midlands. This involved identifying a wide range of providers, such as universities (Higher Education Institutions (HEI)), colleges (Further Education Institutions (FEI)), private providers, Primary Care Trusts (PCTs) and hospices, and investigating the courses they offered. This was done by conducting an initial search of websites and prospectuses, followed by contacting relevant personnel for the different providers to find out more information about the courses. The search for training and education courses took place between September and November 2010, so courses developed since November 2010 have not been included in this work. A full list of the providers used in this project can be found in Appendix 2.

3. Mapping the available training and education courses against the main stages in the West Midlands CPG (Darzi) Dementia Pathway to identify which areas were covered and where there were gaps. Also seeing where the gaps were when comparing existing training to the ‘recommended’ training topics identified in phase 1.

In addition, demographic information for each of the PCTs was obtained where possible, to identify if any PCTs had particular issues with regards to dementia. This information and analysis is contained in Appendix 1.

**Identifying key areas in dementia care and training**

The key areas in dementia care and training which were used when mapping the training and education courses were derived from two different sources. The first source was the West Midlands CPG (Darzi) Dementia Pathway, and the main points identified previously within this report:

- Prevention – healthy lifestyles and who the ‘at risk’ groups are;
- Awareness – raising public awareness and providing information about the different types of dementia;
- Diagnosis – mainly focusing on the processes for diagnosing dementia, but is also assumed to cover ‘signs and symptoms’;
- Advance Care Planning – planning future care and making advance directives;
- Symptom & Pain Management – potential medication, treatments and interventions;
- Carer & Family Support – providing support to carers and family members affected by dementia;
- End of Life & Palliative Care – caring for people with dementia in the latter stages of their lives;
- Bereavement – helping carers and family members deal with their feelings and emotions following the death of a loved one.

Where the contents of a course did not appear to fall into any of the above categories it was classed as ‘Other’.

The second source was a variety of reports and books covering different aspects of dementia (Horstink, 2009; Marie Curie, 2009; NICE, 2010; Brooker, 2007; Kitwood, 1997 and Nuffield Council on Bioethics, 2009). In this literature, a number of topics or themes kept arising as being important to dementia care. While some fitted directly into the areas within the West Midlands CPG (Darzi) Dementia Pathway, others spanned more than one part of it. Not every topic could be included, but a range of the most widely reported ones were identified and used as ‘recommended’ topics when mapping the courses:

- Types of dementia
- Services available
- Signs and symptoms
- Timely diagnosis
- Communication and support following diagnosis
- Decision making/advance directives
- Involving the patient and carer
- Mental Capacity Act
- Person centred care/individualised care
- Pain assessment
- Challenging behaviour
- Communication with the patient
• Medication/treatments/interventions
• Communication with the carer
• Dying with dignity - the good death
• Carer and family support in bereavement

Where the contents of a course did not appear to fall into any of the above categories it was classed as ‘Other’.

Investigating training and education courses

Types of course
For this work, information was gathered for three categories of training and education course:

1. Dementia specific courses - these courses had dementia as the main topic and generally included dementia in the course title;
2. Dementia related courses - these courses were not specifically focused on dementia but included it as part of a wider range of topics covered or as an example of a long term condition/mental health condition/end of life condition etc.;
3. Other relevant courses - these courses did not include dementia as far as it could be established, but did cover topics which were still relevant to end of life care or could be appropriate to caring for people with dementia.

When searching for different types of course identified above, it was noted that the subject was not treated consistently by all providers. Some providers classed dementia as a long term condition while others classed it under end of life, palliative care, mental health conditions, non-malignant diseases or ageing. It should therefore be recognised that although the course search was as thorough as possible, some courses may still have been overlooked if they were hidden away under a more obscure topic. However, if a course was missed because it was difficult to find it is unlikely that many people would know about it and want to take it.

It should also be noted that some providers offered courses that were actually run by other providers, and where this was the case the course was classed
under the actual provider, i.e. if a PCT offered a dementia course but it was run by a hospice, it was included as a hospice course. A diagram showing some of the links between providers can be found in Appendix 3.

Courses offered by Higher Education Institutions

HEIs are universities, which offer a wide range of undergraduate and postgraduate degrees comprised of different modules. Some HEIs also offer certificates and diplomas, or courses which have no formal qualification. For the purpose of this work, these courses are classed as ‘standalone as they are not related to a degree. Within the West Midlands there are 11 HEIs, and a list of these can be found in Appendix 2.

An overview of the courses currently offered by these 11 HEIs can be seen in Table 1, which shows both the number (and %) of HEIs offering different types of training, and the number of courses.

<table>
<thead>
<tr>
<th></th>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
<th>No relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td>HEI</td>
<td>3 (27%)</td>
<td>8 (73%)</td>
<td>6 (55%)</td>
<td>3 (27%)</td>
</tr>
<tr>
<td>Courses</td>
<td>11</td>
<td>35</td>
<td>64</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 1 – Overview of HEI courses

It can be seen from Table 1 that over a quarter of the HEIs in the West Midlands (27%) do not offer any training and education courses relating to dementia at all, while the same percentage offer 11 dementia specific courses between them. A breakdown of the dementia specific and dementia related courses is shown in Graph 1.
Graph 1 – Breakdown of the types of course offered by HEIs

As seen in Graph 1, the majority of the courses are modules which generally involve approximately five days of teaching, although there are also a reasonable number of degree courses taking 3-5 years. These formal, structured courses tend to be aimed at people working in or towards professional medical careers, as the chance to go into more depth during a longer course is more appropriate for them than for a carer.

The ‘Other relevant training’ courses have been classified into a few key areas as shown in Graph 2.

Graph 2 – Breakdown of the ‘Other relevant training’ course offered by HEIs
It can be seen that the topics are all quite broad, reflecting the fact that HEIs cater for a wide audience without specialising in any particular area. Although the topics relevant to the end of life phase (palliative care, end of life care and bereavement) were individually not as well represented as other topics, together they represented over a quarter of the courses identified.

One of the benefits of courses provided by HEIs is that they tend to be offered every academic year. However, this does not guarantee that they will actually run every year as HEIs require minimum student numbers before a course will go ahead. A couple of the HEIs contacted for this project commented that some of their courses were not being run this academic year due to low student numbers. If HEIs do not see sufficient demand for dementia courses they may decide not to offer them in the future, or at the very least not develop their existing courses. The number and scope of dementia courses could therefore begin to decline and have an impact on dementia training.

Courses offered by Further Education Institutions

FEIs are colleges, which tend to offer a wide range of vocational courses and adult education courses. The teaching is less formal than in HEIs, and some courses do not result in a formal, recognised qualification. 31 FEIs within the West Midlands were contacted for this work, and a list of these can be found in Appendix 2.

An overview of the courses offered by FEIs can be seen in Table 2, which shows both the number (and percentage) of FEIs offering the different types of courses, and the number of courses.

<table>
<thead>
<tr>
<th></th>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
<th>No relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEI</td>
<td>15 (48%)</td>
<td>1 (&lt;1%)</td>
<td>11 (35%)</td>
<td>14 (45%)</td>
</tr>
<tr>
<td>Courses</td>
<td>18</td>
<td>3</td>
<td>25</td>
<td>-</td>
</tr>
</tbody>
</table>

*Table 2 – Overview of FEI courses*

Although a significant number of the FEIs offered no relevant training courses, nearly half of them (48%) actually offered dementia specific courses. However, it should be noted that some of the dementia specific courses are actually the same
at different FEIs as they are standard qualifications. One example is the NCFE (formerly the Northern Council for Further Education) Certificate in Dementia Awareness, where students follow the same units regardless of the FEI.

![Graph 3 – Breakdown of the types of course offered by FEIs](image)

The use of standard qualifications across different FEIs is reflected in Graph 3, where nearly half of the courses on offer are an NCFE or similar standard course. These courses generally involve ½-1 day learning per week for 3-4 months, which should allow dementia to be covered in reasonable depth. There is also a high number of standalone courses without a qualification, which could suggest that the courses are developed in a less standardised manner and on a more individual basis by different FEIs. These are generally ½ or 1 day courses aimed more at carers, care workers and nursing home staff than at medical professionals.

The courses classed as ‘Other relevant training’ are broken down into the key areas shown in Graph 4.
Graph 4 – Breakdown of the ‘Other relevant training’ course offered by FEIs

As with the HEIs courses, the topics are quite broad, as FEIs also cater for a wide audience specialising in any particular area. The end of life phase is also well covered, as the end of life care, palliative care and bereavement courses account for nearly half of the ‘Other relevant training’. However, it should be remembered that although these courses are relevant to caring for people with dementia, they do not actually cover dementia or consider end of life care from a dementia perspective.

As with HEIs, FEIs offer the majority of their courses every year, but they can also have the same problems in terms of low student numbers. One FEI said that they offered two dementia courses a couple of years ago but due to insufficient interest neither of them actually ran and they are no longer available. Many FEIs have a business section, which focuses on providing courses on an ad-hoc basis for businesses and companies when there is sufficient demand, rather than on a regular basis for individual members of the public, and sometimes this is the only way that dementia courses can be offered.

**Additional courses offered by FEIs**

As well as the courses identified above, the FEIs offered an additional range of courses which could be an important source of dementia training. Many FEIs offered National Vocational Qualifications (NVQs) and Business and Technology Education Council (BTEC) courses in Health and Social Care. These courses have
been kept separate as both types are in the process of moving from the National Qualification Framework (NQF) to the Qualification and Credit Framework (QCF), so their contents could change. In addition, many of their units are optional and may not necessarily be available at all FEIs.

The new QCF NVQs will provide specialist routes in dementia care and learning disabilities, while both the old and new versions of the level 3 BTECs include a unit on dementia care\(^1\). The level 1 and level 2 QCF BTECs are not expected to cover dementia, but may still include topics that are relevant to dementia care in general. A summary of the range and number of NVQs and BTECs offered by the 31 FEIs is given in Table 3.

<table>
<thead>
<tr>
<th>FEI Courses</th>
<th>2</th>
<th>55</th>
<th>28</th>
<th>25</th>
<th>18</th>
<th>33</th>
<th>32</th>
</tr>
</thead>
</table>

\(1\) More information about QCF NVQs and BTECs can be found at [http://www.edexcel.com/subjects/Health-Social-Care/Pages/Qualifications.aspx](http://www.edexcel.com/subjects/Health-Social-Care/Pages/Qualifications.aspx)

It can be seen that the vast majority of FEIs offer NQF NVQs and NQF BTECs, making them widely available, and one FEI has already moved across to advertising the new QCF NVQs. There could potentially be a further 71 courses with a dementia care pathway if all of the other FEIs currently offering NQF NVQ courses do the same.

BTECs and NVQs are also quite substantial in nature as they are comprised of multiple units. The Dementia Care unit in the level 3 BTEC is recommended to take 30 hours of guided learning to complete, while the NVQ units are approximately 20-25 hours each and the Dementia Care pathway would probably involve four dementia units. This means that it should be possible to cover a range of dementia topics in a good level of detail.

It should be noted that although care homes, residential homes and nursing homes were not included in this work, the National Care Standards (DH, 2001)
require a minimum of 50% of trained members of staff to have at least a level 2 NVQ, such as the NVQ in Health and Social Care, or equivalent. This suggests that it is an important qualification which could potentially be very relevant to caring for people with dementia, and should not be ignored when looking at dementia training.

**Courses offered by Private Providers**

Private providers cover a variety of different organisations and are essentially providers of training and education courses who do not fall within any of the other categories of provider. 16 private providers were contacted for this work, focusing on ones specifically within the West Midlands rather than those offering training nationally. It is recognised that this is not a comprehensive set of providers, but provides a representative snapshot of the training available across the region. A list of the private providers is given in Appendix 2.

Some private providers were connected with their local councils and were often used by PCTs to provide training courses. For example, both Shropshire County PCT and Telford & Wrekin PCT use Shropshire Council’s County (Joint) Training for a range of courses, and Education for Health has been used by practically every PCT in the West Midlands. As mentioned previously, a diagram showing some of the links between providers can be found in Appendix 3.

An overview of the courses offered by the private providers can be seen in Table 4, which shows the number (and %) of private providers offering the different types of training and the number of courses. Two providers only offered BTEC and NVQ courses, and so are not included in Table 4. As only private providers offering appropriate courses were chosen, there is no column for ‘No relevant training’.

<table>
<thead>
<tr>
<th></th>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private providers</td>
<td>7 (50%)</td>
<td>1 (7%)</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>Courses</td>
<td>21</td>
<td>3</td>
<td>27</td>
</tr>
</tbody>
</table>

*Table 4 – Overview of courses from private providers*
As can be seen from Table 4, 50% of the private providers offered a total of 21 dementia specific courses. All of these were classed as being standalone, in that they did not have a formal qualification associated with them. As they all only lasted 1-2 days this is not necessarily a bad thing, as offering a qualification for such a course could give a false impression that no further dementia training is required. The courses are also aimed at a wide range of people, including carers, members of the public and medical professionals such as PCT staff.

The ‘Other relevant training’ courses can be broken down into a few key areas as shown in Graph 5.

![Graph 5 – Breakdown of the ‘Other relevant training’ course offered by private providers](image)

The end of life phase was not really covered, with only a few bereavement courses being identified. However, as only private providers offering appropriate courses were investigated for this work, the set of ‘Other relevant training’ is not totally representative of the range of end of life courses offered by all private providers in the West Midlands.

As with the FEIs, many private providers offered NVQs which are currently undergoing a transition to the new QCF structure. As part of a previous project\(^\text{2}\) a number of companies offering NVQs were identified, so these were considered for this project within the list of 16 providers.

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As can be seen in Table 5, the majority of private providers offered NVQs, which could potentially provide 29 courses offering a dementia care pathway under the new QCF structure in the future. This again indicates that NVQs could be an important source of dementia training.

Courses offered by PCTs

PCTs are part of the NHS and provide or commission some primary and community services. There are 17 PCTs within the West Midlands, and a full list of these can be found in Appendix 2. Additional information about the demography of each PCT is also available in Appendix 1. PCTs use a range of external providers such as FEIs, HEIs, private providers and hospices for their training courses. Only courses provided ‘in-house’ by the PCTs were considered here, and an overview of these courses can be seen in Table 6.

<table>
<thead>
<tr>
<th>Private providers</th>
<th>NVQ 2</th>
<th>NVQ 3</th>
<th>NVQ 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Courses</td>
<td>12 (75%)</td>
<td>11</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 5 – NVQ courses on offer from private providers

Less than a quarter of the PCTs offer their own dementia specific and dementia related courses, but this is probably because of the high use of external providers. However, it should be noted that one PCT listed approximately 300 available courses (including those from external providers) and only one of them was a dementia course. Although full training lists were not available for all PCTs to see if the situation was the same elsewhere, dementia courses were generally few and far between. While this suggests that dementia is seriously under-represented, especially in terms of ‘in-house’ courses, some PCTs do actually offer a good range of dementia training through external providers. PCTs that currently do not offer much dementia training are recognising the

<table>
<thead>
<tr>
<th>Courses</th>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCTs</td>
<td>4 (24%)</td>
<td>3 (18%)</td>
<td>15 (88%)</td>
</tr>
<tr>
<td>Courses</td>
<td>9</td>
<td>5</td>
<td>62</td>
</tr>
</tbody>
</table>

Table 6 – Overview of ‘in-house’ courses from PCTs

3 A diagram showing links between different providers can be found in Appendix 4.

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need for change and some are in the process of developing dementia programmes to increase their training portfolios.

The courses offered by PCTs are all standalone, and tend to last from \(\frac{1}{2}-3\) days to fit in with work schedules, and many are available as e-learning courses. While this can be useful as learning can take place at a suitable time, place and pace, it can also be inappropriate in some cases. A point raised by one PCT member of staff was that many staff are not desk-based and do not have dedicated access to a computer. They may have to share a computer with a number of other staff and only use it to input records or data as part of their daily routine. This can mean that e-learning courses are inappropriate as staff are not able to use a computer for the required period of time without affecting other users, and also many staff are not overly confident or comfortable using computers anyway. In such cases, more formal or structured face-to-face courses are preferred.

The ‘Other relevant training’ courses are broken down into a few key areas and shown in Graph 6.

![Graph 6 - Breakdown of 'Other relevant training' course offered by PCTs](image)

The main areas for ‘in-house’ PCT training were safeguarding and mental capacity, which could be because they are the most relevant topics for the widest range of staff, i.e. they are not specialist areas as such but topics that all staff should be aware of, making them worth providing ‘in-house’. The end of life
phase represented less than a quarter of the courses, but it is recognised that more training in these areas was obtained from other providers.

It should be noted that like FEIs and private providers, some PCTs offered NVQs in Health and Social Care. As discussed previously, these could be a potential source of dementia training in the future if/when they transition to the QCF structure. As indicated in Table 7, this could affect an additional eight courses.

<table>
<thead>
<tr>
<th>NVQ 2</th>
<th>NVQ 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCTs</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Courses</td>
<td>4</td>
</tr>
</tbody>
</table>

*Table 7 – NVQ courses on offer from PCTs*

**Courses offered by Hospices**

Hospices provide palliative care for patients with terminal illnesses, often at their own location but sometimes in the patient’s home. Hospices play an important role in end of life care, but have traditionally been associated with cancer patients. In (Blackwell, 2008) it says that 93% of hospice patients have cancer, and the place of death for cancer and non-cancer patients can be very different as shown in Table 8.

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Cancer deaths</th>
<th>Non-cancer deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice</td>
<td>16%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Home</td>
<td>25%</td>
<td>17%</td>
</tr>
<tr>
<td>Hospital</td>
<td>47%</td>
<td>61%</td>
</tr>
<tr>
<td>Care home</td>
<td>10%</td>
<td>21%</td>
</tr>
</tbody>
</table>

*Table 8 – Location of death for cancer and non-cancer patients*

22 hospices and two homecare services were identified in the West Midlands region, and a full list of them can be found in Appendix 4. The majority of the hospices are located in the West Midlands county itself around the Birmingham area, and the locations and coverage areas of the hospices can be seen in Appendix 4, together with an overview of the main information about each hospice.

An overview of courses currently offered by hospices can be seen in Table 9, which shows the number (and %) of hospices offering different types of training, and the number of courses.
<table>
<thead>
<tr>
<th></th>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
<th>No relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospices</td>
<td>9 (38%)</td>
<td>3 (13%)</td>
<td>11 (46%)</td>
<td>13 (54%)</td>
</tr>
<tr>
<td>Courses</td>
<td>6*</td>
<td>6**</td>
<td>110</td>
<td>-</td>
</tr>
</tbody>
</table>

* One course is offered by three hospices. Two courses have already taken place and it is not clear if they will be repeated
** One course has already taken place and it is not clear if it will be repeated

Table 9 – Overview of hospice courses

It can be seen that over half of the hospices (54%) do not offer any relevant training, and there are only a few dementia specific and dementia related courses on offer. Most of those courses are standalone, but 3 of the dementia related courses are modules offered as part of a university degree. The standalone courses generally last ½ - 1 day, while the modules each have 5 days of learning.

The courses classed as ‘Other relevant training’ can be broken down into a few key areas as shown in Graph 7.

Graph 7 – Breakdown of the ‘Other relevant training’ course offered by Hospices

It can be seen that over half of the courses were in the end of life phase (palliative care, end of life care and bereavement), with pain/symptom management also featuring highly. This is to be expected as these areas represent the stage at which hospices generally become involved in patient care. Any of these areas could potentially apply to caring for people with dementia, and many of the principles covered in the courses would be relevant even if dementia is not specifically mentioned.
The provision of training courses varied greatly between hospices, ranging from having no education unit or courses, through to forming a group with other hospices to offer a common set of courses and linking with universities and PCTs.

For some of the hospices, the training courses offered were not fixed but were regularly updated and changed. This means that if a dementia course is available one year it is not guaranteed to be offered the following year, and conversely dementia may be more likely to be covered if it was not covered the previous year. A common theme across all hospices that offered training was that while palliative care and end of life issues were covered, very few courses were either dementia specific or dementia related. Both of these indicate that dementia is not necessarily seen as a key area by hospices, even though many do accept patients with dementia. In some cases, instead of providing staff with dementia training a hospice will use specialist nurses such as Macmillan nurses to help care for dementia patients when required.

However, hospices do appear to be realising that the situation is changing, and some are in the process of finding out about getting training courses from other providers or extending current training plans. In fact, since carrying out the initial search for existing training courses, a group of hospices has actually begun working with Dementia UK and the University of Worcester to develop a one-day and a five-day training programme covering advance care planning and end of life care for people with dementia, which will both be run on multiple occasions within the West Midlands. In addition, some hospices are also happy for students to write course assignments with a focus on dementia care if it is their area of work or a topic of particular interest for them, even if the course itself does not cover dementia.

Unfortunately, in some cases although the move away from caring just for cancer patients has been recognised, the move towards including dementia patients has yet to fully materialise. This can be seen in the following description of a course offered by one of the hospices, which is used as an example of a
number of courses on offer where the range of conditions has expanded but not quite as far as including dementia.

<table>
<thead>
<tr>
<th>The Management of Life Threatening Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a growing recognition of the inequality of palliative care services for non-cancer conditions. This day aims to highlight the importance of the need for equity to all patient groups.</td>
</tr>
<tr>
<td>Heart failure</td>
</tr>
<tr>
<td>End stage respiratory disease</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
</tr>
<tr>
<td>Motor neurone disease</td>
</tr>
<tr>
<td>Renal failure</td>
</tr>
</tbody>
</table>

Overall summary of the courses on offer

An overview of the number of courses offered by all of the providers investigated for this project\(^5\) can be seen in Table 10, and although the number of dementia specific and dementia related courses does not seem particularly low, it should be remembered that they represent a very small portion of the total number of courses offered in the West Midlands\(^6\), making dementia training a niche area.

<table>
<thead>
<tr>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td>65</td>
<td>52</td>
<td>288</td>
</tr>
</tbody>
</table>

Table 10 – Overview of courses offered in the West Midlands

The courses were also considered in terms of the location of the providers, to see if there is a difference between counties. The results can be seen in Table 11. It is recognised that while training may be provided in a specific county it could actually be accessed in other counties as well, and there was a lot of cross-county training taking place. These results should therefore only be used as an indication of training provision.

---

\(^5\) 99 providers in total

\(^6\) The total number of courses on offer has not been established, but is estimated to be in the order of multiple thousands.

© Association for Dementia Studies 2011
<table>
<thead>
<tr>
<th>County</th>
<th>Dementia specific</th>
<th>Dementia related</th>
<th>Other relevant training</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hospice</td>
<td>Non-hospice</td>
<td>PCT</td>
</tr>
<tr>
<td>Birmingham</td>
<td>-</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Coventry</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Herefordshire</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Shropshire</td>
<td>1</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>Staffordshire</td>
<td>2</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Warwickshire</td>
<td>-</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>West Midlands</td>
<td>1</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Worcestershire</td>
<td>1</td>
<td>5</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 11 – Course provision by county

Coventry, Herefordshire and Warwickshire had low numbers of courses, but have good connections with other counties and so can benefit from their training provision. Staffordshire had a high number of courses, with the majority of those being provided by one hospice and one HEI, and similarly most of the non-hospice courses in Shropshire were run by one private provider. These examples indicate how a single provider with a good range of courses can have a significant impact on the training available in a county. It should be noted that while the West Midlands county had the highest number of PCT courses, it does encompass multiple PCTs, unlike counties such as Herefordshire, Warwickshire and Worcestershire where there is only one PCT for each.

A breakdown of the types of course offered is shown in Graph 8, and indicates that most dementia specific courses are likely to be standalone, while dementia related courses are more likely to be more formally taught modules or degrees, resulting in a qualification.
Although little information was available about resources used by the courses, the general impression was that the standalone courses tended to be discussion based, incorporating personal experiences from both the course leaders and the students, and also including carer stories where possible. The use of DVDs/video clips was occasionally mentioned, such as ‘Darkness in the afternoon’ (Chapman, 2002) and ‘Yesterday, today, tomorrow: providing quality dementia care’ (Alzheimer’s Society, 2002).

A breakdown of the ‘Other relevant training’ courses is provided in Graph 9.

Graph 8 – Breakdown of type of courses offered in the West Midlands

Graph 9 – Breakdown of ‘Other relevant training’ courses offered in the West Midlands
It can be seen that the end of life phase was strongly represented by more than a third of the available courses. These courses were aimed more at professionals, and tended to include case studies or examples to support the learning. Clinical practice or placements were also used, enabling students to gain practical experience. However, as these courses were not dementia focused, these placements are unlikely to include caring for, or even meeting, people with dementia.

The ‘Other relevant training’ courses will be considered in more detail when looking at training gaps, as they tie in well with the key areas in dementia care identified previously, showing that their principles could easily be applicable to caring for people with dementia. Many of the topics are also inter-linked, for example Advance Care Planning is related to Mental Capacity, which in turn has a strong connection to Mental Health, suggesting that they may be able to help address a wider range of training gaps.

The BTEC and NVQ courses are summarised in Table 11, and are considered in more detail when looking at training gaps, as they are an important potential source of training which is worth monitoring during the transition to the QCF structure. 165 courses do or could cover dementia, more than doubling the number of dementia specific and dementia related courses summarised previously in Table 10.

<table>
<thead>
<tr>
<th>Courses</th>
<th>Potential to cover dementia (2)</th>
<th>Other relevant training (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>57</td>
<td>108</td>
<td>65</td>
</tr>
</tbody>
</table>

(1) BTEC level 3 and QCF
(2) NVQ level 2, 3 & 4
(3) BTEC level 1 & 2

Table 12 –Summary of BTEC and NVQ courses offered in the West Midlands

The BTEC and NVQ courses were also considered in terms of the location of their provider, and can be seen in Table 13.
As with Table 11, Table 13 indicates that the fewest BTEC and NVQ courses were offered in Coventry, Herefordshire and Warwickshire, while Staffordshire and the West Midlands had the highest number of courses. However, overall the different counties tended to have a reasonable number of BTEC and NVQ courses available, suggesting that there is access to these courses across the West Midlands.

### Mapping the training and education courses

The available information on the course content of each dementia specific and dementia related course offered in the West Midlands was used to map the courses against the West Midlands CPG (Darzi) Dementia Pathway and the list of ‘recommended’ topics identified previously. Each course could cover multiple topics and parts of the pathway. If a course did not appear to cover any of the identified areas it was classed as ‘Other’. These mappings were converted to show the percentage of courses covering each area or topic, and are shown in Graph 10 and Graph 11.

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7 65 dementia specific and 52 dementia related courses were used in the mappings process.

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Course mapping against the West Midlands CPG (Darzi) Dementia Pathway

Graph 10 – Mapping of courses against West Midlands CPG (Darzi) Dementia Pathway

Mapping of dementia specific courses

In general, the focus of the dementia specific courses was on awareness of dementia and caring for people with dementia (over half of the courses were called ‘Dementia Awareness’ or ‘Dementia Care’), rather than on the end of life phase.

As can be seen from Graph 10, the only area that was covered by more than 50% of the dementia specific courses was dementia awareness, especially the different types of dementia. This is not particularly unexpected as many dementia courses are likely to include at least a brief overview of what it is. The areas with the next highest coverage were diagnosis, although the focus was mainly on signs and symptoms rather than how to diagnose dementia, and symptom/pain management, which generally focused on the medical options available.

Prevention was not mentioned in any course description, but this may be because dementia specific courses assume that the patient already has dementia, so prevention is not relevant. Prevention could be covered by health promotion courses instead, and these courses were not necessarily identified in this work. Also, based on emerging research dementia prevention is closely linked to
prevention of vascular disease, so future education in this area could form part of a wider framework of health risks.

The end of life phase (end of life care/palliative care and bereavement) was only covered by 15% of courses, with no course descriptions mentioning bereavement at all. The majority of palliative care courses were run by hospices as this is their field of work, so these areas could be seen as specialist or less of a priority in wider training circles.

**Mapping of dementia related courses**

There was a shift in results when mapping the dementia related courses, for example coverage of awareness and diagnosis was a lot lower. This could be because less time is devoted to dementia on these courses, and if dementia is used as an example condition there may be an assumption that the students already have sufficient background knowledge of it.

Prevention was still barely covered, but again this could be due to relevant health promotion courses not being identified. Coverage of the end of life phase was a lot higher with 42% of courses covering end of life/palliative care, and 12% of courses covering bereavement. Advance Care Planning was still not covered widely at 13%, but was better than in the dementia specific courses where it was only covered by 6% of the courses.

Overall, these results showed that no individual course covered all areas of the dementia pathway, and both the dementia specific and dementia related courses had limitations and were weaker in some areas. However, they are both important sources of dementia training, as the dementia specific courses provide deeper knowledge of dementia and an introduction to a range of areas, while dementia related training provides a deeper knowledge of the areas and how they are relevant to dementia.
Course mapping against the ‘Recommended’ topics

### Mapping of courses against recommended topics

<table>
<thead>
<tr>
<th>Topic</th>
<th>Dementia specific (%)</th>
<th>Dementia related (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of Dementia</td>
<td>50</td>
<td>10</td>
</tr>
<tr>
<td>Services Available</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Signs and Symptoms</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Timely Diagnosis</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Communication Following Diagnosis</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Decision Making/Advance Directives</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Involving the Patient and Carer</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Mental Capacity Act</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Person Centred/Individual Care</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Pain Assessment</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Challenging Behaviour</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Communicating with the Patient</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Medication/Treatment/Interventions</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Communication with the Carer</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Dying with Dignity - The Good Death</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Carer and Family Support in Bereavement</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

**Graph 11 – Mapping of courses against ‘Recommended’ topics**

### Mapping of dementia specific courses

As can be seen from Graph 11, ‘types of dementia’ was covered by over 50% of the dementia specific courses which, due to the number of dementia awareness courses mentioned previously, was not unexpected. Person centred care was also a strong topic covered by 45% of courses, which is promising as it means that there is a strong emphasis being placed on recognising that someone with dementia is still a person. However, involving the person with dementia in their care and the decision making process were both very poorly covered. This was also the case for the end of life phase, with only 3% of courses covering dying with dignity and no courses covering bereavement.

The phase covering challenging behaviour, communicating with patients and medication/treatment/interventions was better covered than many, with the three topics having 26%, 32% and 26% coverage respectively. However, coverage of pain assessment was very low at just 5%, which was surprising as it was expected that it would be connected to these topics. It may be that pain...
assessment was not specified in the course details but is actually covered when talking about the related areas, but even if this was the case, pain assessment would still not be covered in a great number of courses.

**Mapping of dementia related courses**

None of the individual topics was covered by more than 30% of the courses, with medication/treatment/interventions having the highest coverage at 27%. After this, the dementia related courses provided better coverage of topics that are not specific to dementia but where dementia can be used as an example condition, e.g. Mental Capacity Act, communication with the patient and bereavement support, which were all covered by 15% of courses. There were also more ‘Other’ courses for the same reason, as safeguarding, patient rights and mental health are all areas that can apply to a range of patients rather than just to those with dementia.

Overall, topics relating to communication or to the carer rather than the person with dementia had low coverage rates, suggesting that they are not considered to be the main focus or priority in dementia care.

**Identified training and education gaps**

Using the results from the course mappings, it was found that the areas that were covered best by the courses were improving awareness of dementia, especially the types, signs and symptoms of dementia, and treating and caring for a person with dementia.

The main gaps identified in the training and education courses were:

- Dementia prevention, although this may be covered by other courses;
- Advance care planning and involving the patients in care and decision making following diagnosis;
- Bereavement, especially in dementia specific courses;
- Pain assessment as part of symptom/pain management.

The main areas for improvement were considered to be:

- Carer support and involvement;
End of life care, especially in dementia specific courses. Without the hospice courses, this area would be a lot more worrying.

This is not to say that courses looking at other areas should stop being developed, but that the ones highlighted above have more cause for concern.

Several course providers also commented on where they considered there to be gaps in current training or areas that could be improved. As the following comments indicate, the areas raised by the providers tended to match the gaps and areas for concern identified in this work:

- "The specialist palliative care needs of dementia patients, what it is, who and how it should be provided" - Hospice
- "More focus on pain assessment and ethical issues such as advance care planning" - Hospice
- "How to balance the needs of dementia patients with the needs of other patients" - Hospice
- "Community Health Services, Intermediate Care and the end of life crossover where a person is dying with dementia" - PCT

It can be seen from some of the above comments that the end of life phase was recognised as being an important part of the dementia journey, but one that not much is known about in relation to dementia. This matches the course analysis carried out for this work which found that although a good number of ‘Other relevant training’ courses address end of life issues, dementia-specific end of life training was an area requiring improvement.

**Potential ways to address the identified training gaps**

It is recognised that course development is an ongoing process, and the information contained in this report represents a single snapshot of the courses available, so it is possible that some of the training gaps are already being addressed. For example, the Association for Dementia Studies at the University of Worcester is in the middle of developing a range of courses covering various aspects of dementia, including end of life care. However, the remainder of this section considers potential ways to address training gaps based on the
information available as a result of the course search, which was conducted between September and November 2010.

To see whether the new QCF versions of the BTEC and NVQ courses could address some of the training gaps identified previously, they were also mapped against the same areas of the West Midlands CPG (Darzi) Dementia Pathway and the ‘recommended’ topics. For the BTEC course only the dementia care unit was considered, and for the NVQ only the dementia units forming the dementia pathway were mapped. These mappings are shown in Table 19 and were done as a check list rather than a percentage as it is currently not clear which providers, and therefore how many courses, will be continued under the QCF structure.

<table>
<thead>
<tr>
<th>West Midlands CPG (Darzi) Dementia Pathway</th>
<th>QCF BTEC</th>
<th>QCF NVQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awareness</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Advance care planning</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Symptom/pain management</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Carer/family support</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>End of life/palliative care</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Bereavement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 14 – Mapping of QCF BTEC and QCF NVQ courses against West Midlands CPG (Darzi) Dementia Pathway

As can be seen from Table 14, the QCF NVQ has the slightly wider scope of the two courses, covering six of the dementia pathway areas compared to four for the QCF BTEC. Neither course covers prevention or bereavement, so would not be able to address those gaps, but the QCF NVQ course does cover advance care planning to some extent so would be a useful training source to monitor. It also covers end of life for dementia patients, although the unit descriptions gave the impression that it is not covered in much depth.
<table>
<thead>
<tr>
<th>Recommended topics</th>
<th>BTEC/QCF</th>
<th>NVQ/QCF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of dementia</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Services available</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Signs and symptoms</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Timely diagnosis</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Communication following diagnosis</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Decision making/advance directives</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Involving the patient and carer</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Mental Capacity Act</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Person centred/individual care</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Pain assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Challenging behaviour</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Communicating with the patient</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Medication/treatment/ interventions</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Communication with the carer</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Dying with dignity – the good death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer and family support in bereavement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (Nutrition)</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>

Table 15 – Mapping of QCF BTEC and QCF NVQ courses against ‘Recommended’ topics

Table 15 shows that both courses also cover a wide selection of ‘recommended’ topics, but again the QCF NVQ course has the wider scope covering all but three of the topics to some extent. In particular, it covers the phase following diagnosis and has more emphasis on including the carer, which were topics that were not well covered by the main dementia courses. However, pain assessment and the topics linked to the end of life phase are not covered by either course, so they would not be able to fill or improve these gaps.

Both the BTEC and NVQ courses cover a wide range of topics with a specific focus on dementia and dementia patients. They would therefore be an important source of dementia training and could be used to help with some of the gaps or areas for improvement previously identified.

In addition to the QCF courses, the ‘Other relevant training’ courses could be useful when addressing the training gaps. The contents of these courses was not examined in great detail due to the number of courses involved, but two courses from each topic were looked at more closely to see if they covered a wider range.
of topics than the main one used for their classification. This quick study found that many courses overlap multiple topics, for example courses on Mental Capacity Act and long term conditions can also cover areas linked to advance care planning. When considering the ability of these courses to help address some of the training gaps only the main topic was used, but it is recognised that a course could be applicable to more than one area.

The ‘Other relevant training’ courses could help with the advance care planning gap as there were a few courses specifically on this topic and it was also covered in others. Bereavement is another area that could be improved as a lot of courses existed covering both sudden and expected death, potentially making them appropriate to the death of a dementia patient. Carer support and involvement could be addressed by the end of life, palliative care and bereavement courses, although issues specific to dementia would probably not be covered. The large number of end of life and palliative care courses could also help to address the gap in these areas, and although they would not necessarily include caring for dementia patients many principles could still be applicable. This may also be the case with the pain management courses as they include pain assessment but may not specifically cover pain assessment for dementia patients.

A summary of how the QCF and ‘Other relevant training’ courses could be used to address some of the identified training gaps is shown in Table 16.

<table>
<thead>
<tr>
<th>Dementia specific &amp; related courses</th>
<th>+ QCF courses</th>
<th>+ Other relevant training courses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia prevention</td>
<td>Gap or area for concern</td>
<td>Gap or area for concern</td>
</tr>
<tr>
<td>Advance care planning &amp; involving patients</td>
<td>Gap or area for concern</td>
<td>Area for improvement</td>
</tr>
<tr>
<td>Bereavement</td>
<td>Gap or area for concern</td>
<td>Gap or area for concern</td>
</tr>
<tr>
<td>Pain assessment</td>
<td>Gap or area for concern</td>
<td>Gap or area for concern</td>
</tr>
<tr>
<td>Carer support &amp; involvement</td>
<td>Area for improvement</td>
<td>Still need more dementia focus</td>
</tr>
<tr>
<td>End of life care</td>
<td>Area for improvement</td>
<td>Area for improvement</td>
</tr>
</tbody>
</table>

Table 16 – Summary of how training gaps could be addressed by other courses identified
It can be seen from Table 16 that although many of the training gaps, including those relating to the end of life phase, are improved by including these additional courses, none has been filled altogether. For this to happen, new courses would have to be commissioned to specifically address these areas, or existing courses would have to be adapted or updated to include them. Many providers do actually advertise that they can create bespoke or tailored courses on request to meet individual needs and requirements, so there is the potential for either option to be taken forward, especially with providers that already run similar courses.

Conclusions and recommendations

The main finding from this work was that none of the courses identified actually followed the West Midlands CPG (Darzi) Dementia Pathway, resulting in training gaps and areas where improvements should be made. Due to the number and type of providers considered there is also a degree of inconsistency between courses in terms of the contents, duration and the level to which topics are studied. This could potentially affect a number of areas such as how people understand dementia, the interactions between professionals, patients and families, and the end of life experience, for example not respecting a patient’s wishes through not making an advance care plan when they still had mental capacity and the ability to make choices for themselves.

- The West Midlands CPG (Darzi) Dementia Pathway should be used when developing dementia training.
- All areas of the West Midlands CPG (Darzi) Dementia Pathway should be covered by dementia training.

Dementia training is a niche area when compared to the number of courses on offer from individual providers and overall. There are also a few key providers of dementia training, such as hospices and private providers, with most end of life and palliative care training being provided by hospices. However, there is a general recognition that dementia needs to be addressed and included more widely, and training plans are improving.
• To make dementia training more mainstream, access to courses from key providers needs to be improved or a wider number of providers need to offer courses in areas that could be regarded as specialist.

• Training courses should be available/accessible across the whole of the West Midlands and not just in isolated pockets close to key providers.

As existing dementia courses are being cancelled due to low numbers and there is a good range of ‘Other relevant training’ courses available, creating new courses to address training gaps may not necessarily be appropriate or cost effective.

• The scope of existing dementia courses could be widened to cover more parts of the West Midlands CPG (Darzi) Dementia Pathway.

• Other courses could be adapted to include dementia as an example or to link them back to dementia. The aim would not necessarily be to make them dementia specific courses, but courses with a strong dementia element. This would also have the knock-on effect of raising dementia awareness in a wider range of people who may be unlikely to take a dementia specific course.

The NVQ and BTEC transition to the QCF structure could more than double the number of dementia courses available in the West Midlands. These courses are a good source of dementia training and could help to address some of the training gaps and areas for improvement. They are also an important qualification for care home staff, providing a key method for extending dementia training into care homes.

• The QCF transition should be monitored to see which providers continue to offer the courses.

The future of dementia training should build on the base of existing courses and explore the range of options available for consolidating, enhancing and expanding courses to make dementia training and education courses more accessible and wide-ranging in terms of their content, delivery and provider location.
Acronyms

BME  Black and Minority Ethnic
BTEC  Business and Technology Education Council
CPG  Clinical Pathway Group
DeLCaP  Dementia End of Life Care Project
DH  Department of Health
FEI  Further Education Institution
GP  General Practitioner
HEI  Higher Education Institution
NCFE  Formerly the Northern Council for Further Education
NCHSPCS  National Council for Hospice and Specialist Palliative Care Services
NCPC  National Council for Palliative Care
NHS  National Health Service
NQF  National Qualification Framework
NVQ  National Vocational Qualification
PCT  Primary Care Trust
QCF  Qualification and Credit Framework
SHA  Strategic Health Authority

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Appendix 1

PCT demography information
A range of demographic factors can have a significant impact on the likelihood of a person developing dementia, so knowing about the demography of the different PCTs in the West Midlands could help to identify potential issues facing each PCT. Some of these issues may require specific training courses to raise awareness and provide an appropriate level of knowledge in key areas to ensure that services are able to cater for the right population. Some of the main demographic factors are highlighted below, with the Alzheimer’s Society website\(^8\) providing much of the information.

Age and Gender
As can be seen in Table 17, the prevalence of dementia greatly increases with age, but gender can also be a significant factor. Around two thirds of people with dementia are women and dementia is particularly an issue for men ages 65-74 and women aged 80+. Six of the courses identified in the previous section were found to cover dementia in connection with ageing, suggesting that although there is a link between dementia and age it is also recognised that they are separate conditions and dementia is not simply part of the ageing process.

<table>
<thead>
<tr>
<th>Age</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-64</td>
<td>1 in 1400</td>
</tr>
<tr>
<td>65-69</td>
<td>1 in 100</td>
</tr>
<tr>
<td>70-79</td>
<td>1 in 25</td>
</tr>
<tr>
<td>80+</td>
<td>1 in 6</td>
</tr>
</tbody>
</table>

Table 17 – Prevalence of dementia in different age groups

Although most dementia occurs in the 65+ age group, 2.2% of people with dementia are aged less than 65 and have early onset dementia. Age can also affect the type of dementia as overall 62% of people with dementia have Alzheimer’s, but only around one third of people with dementia under 65 have Alzheimer’s. Instead, vascular dementia is more common in under 65s, and younger people are also likely to have rarer forms of dementia such as alcohol related dementia.

As dementia is traditionally associated with older people diagnosis for younger people could be an issue, and many dementia services will not be directed at supporting younger

\(^8\) www.alzheimers.org.uk
people who can have different issues and challenges such as employment, younger children and families, and finances.

**Ethnicity**

People with an Indian, Bangladeshi, Pakistani, Sri Lankan or African-Caribbean ethnic background can have an increased risk of developing vascular dementia. In addition, people from Asian communities generally develop early onset dementia at a rate three times higher than the wider population. This is similar for people from Black and Minority Ethnic (BME) backgrounds in general, as only 2.2% of people with dementia have early onset dementia, but 6.1% of people with dementia from a BME background have early onset dementia. Timely diagnosis and support in areas with higher proportions of people from BME backgrounds is therefore particularly important.

**Other medical conditions**

Existing medical conditions can have an impact on dementia in different ways. For example, diagnosis can be more complicated in people with learning difficulties as their existing condition can mask the symptoms of dementia to some extent, making them harder to identify. Diagnosis can also be difficult in people with Down’s Syndrome for a similar reason, but at the same time they have a significantly higher risk of developing early onset dementia than the wider population. This can be seen in Table 18, which shows the percentage of people with Down’s Syndrome who also have dementia.

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-39</td>
<td>2</td>
</tr>
<tr>
<td>40-49</td>
<td>9.4</td>
</tr>
<tr>
<td>50-59</td>
<td>36.1</td>
</tr>
<tr>
<td>60-69</td>
<td>54.5</td>
</tr>
</tbody>
</table>

*Table 18 - % of people with Down’s Syndrome who also have dementia*

The needs of people with learning difficulties or Down’s Syndrome and dementia may not necessarily be addressed by either learning disability or dementia services. However, seven of the courses identified in the previous section were found to cover dementia in connection with learning disabilities and/or autism, suggesting that the problems raised here are recognised and work is being done to try and address them.

High blood pressure (hypertension) can also have an impact on dementia as it increases the risk of developing vascular dementia. The prevalence of hypertension also differs
depending on ethnicity with the highest prevalence seen among people from a Black Caribbean background. Raising awareness of the risks associated with hypertension and promoting ways to lower blood pressure could therefore be beneficial.

**Lifestyle**
A number of lifestyle choices can also affect dementia, for example for people who smoke the risk of developing Alzheimer’s is almost double the risk for non-smokers. Similarly, mid-life obesity can increase the risk of developing dementia in later life. Drinking is also a big problem as alcohol related brain damage, which is generally caused by drinking excessive amounts of alcohol over a long period of time, is said to account for 10% of dementia cases overall and 12.5% of cases in the under 65s.

**Location and geography**
Although not a factor known to affect dementia, the geography of the area covered by a PCT could have an impact on people with dementia and the training needs of the PCT. For example, access to services such as attending appointments, socialising with other dementia patients and their carers, and home care services could be more difficult in rural areas than in more urban areas. Having patients dispersed over a wider area could also affect the number of staff needing training in different dementia subjects and to what level. Consequently, PCTs with more rural areas are likely to face different issues than PCTs with a predominantly urban geography. It is recognised that this issue is not specific to dementia care, but should still be taken into account.

The following information has been gathered from searching the websites for the 17 PCTs in the West Midlands and various PCT reports that are all available to the public, together with the West Midlands QI Dementia Care Pathway Group report (Seamer, 2009). Where possible, information has also been provided for the West Midlands as a whole and for England to enable comparisons to be made. The information has been split into two tables to make it easier to read, and a summary of the main points follows Table 20.
### Geography, age and ethnicity

<table>
<thead>
<tr>
<th>PCT</th>
<th>Population</th>
<th>Geography</th>
<th>Life expectancy (M/F)</th>
<th>% People aged 65-85 (1)</th>
<th>% People aged 85+ (1)</th>
<th>% People from BME background (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birmingham East &amp; North</td>
<td>437,000</td>
<td>Urban</td>
<td>76/80.5 (2)</td>
<td>~13</td>
<td>~2.1</td>
<td>5-71 (3)</td>
</tr>
<tr>
<td>Coventry</td>
<td>300,000+</td>
<td>Urban</td>
<td>72.2/78.4</td>
<td>12.5</td>
<td>2.2 (4)</td>
<td>~16</td>
</tr>
<tr>
<td>Dudley</td>
<td>306,000</td>
<td>Urban</td>
<td>77/81.7 (5)</td>
<td>15.6 (5)</td>
<td>2 (5)</td>
<td>6.3 (6)</td>
</tr>
<tr>
<td>Heart of Birmingham</td>
<td>270,000+</td>
<td>Urban</td>
<td>74/81-82</td>
<td>~9 (5)</td>
<td>~1.1 (5)</td>
<td>70</td>
</tr>
<tr>
<td>Herefordshire</td>
<td>180,000</td>
<td>Mainly rural</td>
<td>78.1/83</td>
<td>18.2 (4)</td>
<td>2.9 (4)</td>
<td>4</td>
</tr>
<tr>
<td>North Staffordshire</td>
<td>210,000+</td>
<td>Rural and urban</td>
<td>68.5-80.5/75.7-85.1</td>
<td>15.7 (5)</td>
<td>2.3 (5)</td>
<td>1.5</td>
</tr>
<tr>
<td>Sandwell</td>
<td>320,000</td>
<td>Urban</td>
<td>74.2/79.6 (5)</td>
<td>~15 (4)</td>
<td>~2 (4)</td>
<td>20.3</td>
</tr>
<tr>
<td>Shropshire</td>
<td>295,000</td>
<td>Rural</td>
<td>78/84 (7)</td>
<td>~13 (8)</td>
<td>~9 (8)</td>
<td>1.2 (6)</td>
</tr>
<tr>
<td>Solihull</td>
<td>205,300</td>
<td>Mainly urban</td>
<td>78/84</td>
<td>15.3 (7)</td>
<td>2.1</td>
<td>~9 (5)</td>
</tr>
<tr>
<td>South Birmingham</td>
<td>383,000</td>
<td>Urban</td>
<td>~76/81.5 (2)</td>
<td>~13</td>
<td>2 (6)</td>
<td>30 (6)</td>
</tr>
<tr>
<td>South Staffordshire</td>
<td>604,000</td>
<td>Mainly rural</td>
<td>77.7/81.2</td>
<td>9 (9)</td>
<td>7.3 (9)</td>
<td>4.9 (9)</td>
</tr>
<tr>
<td>Stoke-on-Trent</td>
<td>250,000-270,000</td>
<td>Urban</td>
<td>74.5/79.6 (7)</td>
<td>~8 (10)</td>
<td>~8 (10)</td>
<td>6.8</td>
</tr>
<tr>
<td>Telford &amp; Wrekin</td>
<td>168,000</td>
<td>Urban</td>
<td>77/80.8 (7)</td>
<td>~12.3 (4)</td>
<td>~1.6 (4)</td>
<td>5.5 (7)</td>
</tr>
<tr>
<td>Walsall</td>
<td>250,000+</td>
<td>Urban</td>
<td>75.7/80.7 (11)</td>
<td>15.1 (5)</td>
<td>2 (5)</td>
<td>13.6</td>
</tr>
<tr>
<td>Warwickshire</td>
<td>546,000</td>
<td>Rural and urban</td>
<td>78.1/81.7</td>
<td>~15 (4)</td>
<td>~2.2 (4)</td>
<td>6.4 (7)</td>
</tr>
<tr>
<td>PCT</td>
<td>Geography</td>
<td>Age</td>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>---------------</td>
<td>-------------------------------</td>
<td>-------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Population</td>
<td>Rural/Urban</td>
<td>Life expectancy (M/F)</td>
<td>% People aged 65-85 (1)</td>
<td>% People aged 85+ (1)</td>
<td>% People from BME background (1)</td>
</tr>
<tr>
<td>Wolverhampton</td>
<td>236,000+</td>
<td>Urban</td>
<td>75.7/80.3</td>
<td>≈14.5 (4)</td>
<td>≈2.2 (4)</td>
<td>26.9 (4)</td>
</tr>
<tr>
<td>Worcestershire</td>
<td>553,000-558,000</td>
<td>Mainly rural</td>
<td>78.1/81.8</td>
<td>≈13 (7)</td>
<td>≈2.2 (7)</td>
<td>6 (7)</td>
</tr>
<tr>
<td>West Midlands</td>
<td>5,365,300</td>
<td></td>
<td>≈77/81.5 (5)</td>
<td>14.4 (4)</td>
<td>2.2 (4)</td>
<td>13.9 (5)</td>
</tr>
<tr>
<td>England</td>
<td>77.7/81.8 (12)</td>
<td></td>
<td>13.9 (4)</td>
<td>2.2 (4)</td>
<td>16.3 (4)</td>
<td></td>
</tr>
</tbody>
</table>

(1) As % of PCT population  
(2) Figures for 2005-2007  
(3) Figures vary widely between localities within the PCT, so range is 5%-71% for 2006-2009  
(4) Figures for 2008  
(5) Figures for 2007  
(6) Figures for 2001  
(7) Figures for 2006  
(8) Figures are for retirement age (64 for men, 59 for women)-75 and 75+. Figures for 2006 say overall 19.4% aged 65+  
(9) Figures are for 65-75 and 75+ from 2008. England comparison: 8.3% and 7.7%  
(10) Figures are for 65-75 and 75+ from 2006  
(11) Figures for 2003-2005  
(12) Figures for England and Wales, 2007

Table 19 – PCT demographics for geography, age and ethnicity
Medical conditions, lifestyle and dementia information

<table>
<thead>
<tr>
<th>PCT</th>
<th>Medical conditions</th>
<th>Lifestyle</th>
<th>Dementia information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hypertension</td>
<td>Smoking</td>
<td>Excessive alcohol</td>
</tr>
<tr>
<td></td>
<td>prevalence (1)</td>
<td>% (1)</td>
<td>% (1)</td>
</tr>
<tr>
<td>Birmingham East &amp; North</td>
<td>12.4</td>
<td>27 (6)</td>
<td>17 (6)</td>
</tr>
<tr>
<td>Coventry</td>
<td>12.7</td>
<td>27 (7)</td>
<td>57 (binge)</td>
</tr>
<tr>
<td>Dudley</td>
<td>15.4</td>
<td>12-30 (8)</td>
<td>17.7 (binge)</td>
</tr>
<tr>
<td>Heart of Birmingham</td>
<td>10.3</td>
<td>≈25</td>
<td>≈31</td>
</tr>
<tr>
<td>Herefordshire</td>
<td>14.4</td>
<td>20</td>
<td>23 (binge)</td>
</tr>
<tr>
<td>North Staffordshire</td>
<td>14.9</td>
<td>31.1</td>
<td>45 (binge)</td>
</tr>
<tr>
<td>Sandwell</td>
<td>14.7</td>
<td>29</td>
<td>17.3</td>
</tr>
<tr>
<td>Shropshire</td>
<td>14.1</td>
<td>17</td>
<td>33 (men)</td>
</tr>
<tr>
<td>Solihull</td>
<td>14.3</td>
<td>≈23</td>
<td>14 (10)</td>
</tr>
<tr>
<td>South Birmingham</td>
<td>12.3</td>
<td>24.9</td>
<td>27 (men)</td>
</tr>
<tr>
<td>South Staffordshire</td>
<td>12.9</td>
<td>16.8-22.7 (11)</td>
<td>17.7</td>
</tr>
<tr>
<td>Stoke-on-Trent</td>
<td>15.6</td>
<td>33</td>
<td>25</td>
</tr>
<tr>
<td>Telford &amp; Wrekin</td>
<td>12.1</td>
<td>26</td>
<td>34/17 (binge M/F)</td>
</tr>
<tr>
<td>Walsall</td>
<td>13.8</td>
<td>28</td>
<td>14.8 (binge)</td>
</tr>
</tbody>
</table>

© Association for Dementia Studies 2011
<table>
<thead>
<tr>
<th>PCT</th>
<th>Medical conditions</th>
<th>Lifestyle</th>
<th>Dementia information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hypertension prevalence (1)</td>
<td>Smoking % (1)</td>
<td>Excessive alcohol % (1)</td>
</tr>
<tr>
<td>Warwickshire</td>
<td>13.6</td>
<td>21.3 (12)</td>
<td>15</td>
</tr>
<tr>
<td>Wolverhampton</td>
<td>14.5</td>
<td>27 (13)</td>
<td>14</td>
</tr>
<tr>
<td>Worcestershire</td>
<td>13.2</td>
<td>18</td>
<td>≈28 (binge)</td>
</tr>
<tr>
<td>West Midlands</td>
<td>12.1</td>
<td>21</td>
<td>17.3 (binge)</td>
</tr>
<tr>
<td>England</td>
<td>11.3</td>
<td>≈21-24</td>
<td>18 (binge)</td>
</tr>
</tbody>
</table>

(1) As % of PCT population
(2) Based on reported/diagnosed numbers as % of PCT population
(3) Ratio of GP recorded cases to estimated population prevalence (2007-2008) – higher value indicates better diagnosis rate
(4) Figures for 2005-2007
(5) Per 1000 persons with dementia (2007-2008)
(6) Figures for 2007-2008
(7) Figures for 2010
(8) Figures for 2004
(9) 18-34 year olds
(10) Figures for 2005
(11) Figures for 2008
(12) Figures for 2006
(13) Figures for 2007

Table 20 – PCT demographics for medical conditions, lifestyle and dementia information
Summary of demographic findings
The main points for each PCT are reported here as an overview of the areas that may require more/less focus for dementia training.

Birmingham East & North – high level of its population is from a BME background, and nearly half of dementia deaths take place in an acute setting.

Coventry – high level of binge drinking, but excessive drinking is quite low.

Dudley – the prevalence of hypertension and obesity are at the higher end of the scale in comparison to the other PCTs.

Heart of Birmingham – high level of people from a BME background, a low prevalence of hypertension and a higher level of drinking. Both measures of dementia prevalence are low, indicating that it is not great at diagnosing and reporting cases of dementia.

Herefordshire – high life expectancy and more older people. There is a low level of people from a BME background, a low level of dementia deaths in an acute setting and a low level of emergency admissions for dementia patients. It is also one of the more rural PCTs.

North Staffordshire – high life expectancy but is also at the higher end of the scale in terms of hypertension prevalence, binge drinking and smoking when compared to the other PCTs. It has a low level of deaths in an acute setting and a low number of people from a BME background.

Sandwell – fairly high level of people from a BME background and a higher level of smoking than many of the other PCTs. It is quite good at diagnosing and reporting cases of dementia, but also has a high level of dementia deaths in an acute setting and a high level of emergency admissions for dementia patients. These could well be connected, i.e. the number of deaths and admissions associated with dementia is higher because more dementia cases are diagnosed.

Shropshire – quite similar to Herefordshire in that it is generally rural, has a higher life expectancy and more older people, a low level of people from a BME background, a low level of dementia deaths in an acute setting and a low level of emergency admissions for dementia patients. However, it also has lower levels of obesity and higher levels of drinking amongst men.
Solihull – higher life expectancy and a high level of dementia deaths in an acute setting.

South Birmingham – high level of people from a BME background and a higher level of drinking. In a similar way to Sandwell it is quite good at diagnosing and reporting cases of dementia, but also has a high level of dementia deaths in an acute setting and a high level of emergency admissions for dementia patients.

South Staffordshire – the main demographic factor is that it has a low level of people from a BME background.

Stoke-on-Trent – higher levels of hypertension, smoking, drinking and obesity, as well as a high level of dementia deaths in an acute setting.

Telford & Wrekin – the demographic information available for this PCT is fairly average, and only male binge drinking is at the higher end of the scale when compared to the other PCTs.

Walsall – higher level of obesity and smoking, and is poor at diagnosing and reporting cases of dementia.

Warwickshire – at the lower end of the PCTs in terms of its level of obesity, and has a low level of dementia deaths in an acute setting.

Wolverhampton – higher level of people from a BME background and a higher level of obesity.

Worcestershire – lower level of obesity, higher level of binge drinking and a low level of dementia deaths in an acute setting.

Overall, there are generally fewer dementia deaths in an acute setting in the rural PCTs, which also tend to have lower emergency admission rates and higher life expectancies. The PCTs around the Birmingham area have higher levels of people from a BME background, so could potentially have a greater requirement for knowledge of the dementia subjects associated with this population as discussed earlier. In general, higher levels of hypertension and lifestyle conditions were spread across a number of PCTs with no clear pattern emerging.
Appendix 2

Providers investigated for this project

✓ = offer dementia specific courses
* = offer dementia related courses
+= offer other relevant courses

HEIs
Aston University
Birmingham City University ✓ * +
Coventry University ✓ +
Keele University * +
Newman University College *
Staffordshire University ✓ * +
University College Birmingham
University of Birmingham
University of Wolverhampton *
University of Worcester ✓ * +
Warwick Medical School - University of Warwick *

FEIs
Birmingham Metropolitan College
Bournville College ✓ +
Burton College ✓
City College Birmingham
City College Coventry
City of Wolverhampton College
Dudley College ✓
Halesowen College
Henley College Coventry
Herefordshire College of Technology
Kidderminster College
Leek College
Ludlow College ✓
Newcastle-under-Lyme College +
North East Worcestershire College
North Warwickshire & Hinckley College
Sandwell College ✓
Shrewsbury College of Arts & Technology
Solihull College ✓ +
South Birmingham College ✓ * +
South Staffordshire College +
South Worcestershire College ✓
Stafford College ✓ +
Stoke-on-Trent College ✓ +
Stourbridge College +
Stratford-upon-Avon College ✓ +
Telford College of Arts & Technology ✓ +
Walsall College
Warwickshire College ✓ +
Worcester College of Technology ✓

PCTs
NHS Birmingham East & North PCT +
Coventry Teaching PCT +
NHS Dudley PCT ✓ * +
Heart of Birmingham Teaching PCT +
NHS Herefordshire PCT +
NHS North Staffordshire PCT ✓ +
Sandwell PCT +
Shropshire County PCT
Solihull NHS Care Trust +
NHS South Birmingham PCT ✓ * +
South Staffordshire PCT +
Stoke-on-Trent NHS PCT ✓ +
NHS Telford & Wrekin PCT +
Walsall Teaching PCT +
NHS Warwickshire PCT
Wolverhampton City PCT +
NHS Worcestershire PCT * +

Private Providers
Acacia Training ✓ +
Aspiration Training Ltd
Birmingham Care Development Agency ✓
County/Joint Training ✓ +
Coventry Adult Education Service
CWT – Chamber Training
Dudley LEA ✓ +
Education for Health ✓ +
JHP Group Ltd
NTC Training ✓ +
Omega Training Services
Rock House Training
The South Staffordshire Training Association Ltd
SBC Training
Warwickshire County Council ✓ +
Wolverhampton Adult Education Service ✓

Hospices
The list of hospices can be found in Appendix 4.
Appendix 3

Connections between course providers

Figure 2 below shows the connections and interactions between a number of the course providers. The majority of these connections involve one provider running a course with or on behalf of another provider, but some connections relate to PCTs being in charge of hospices or providers being part of a group such as Compton Hospice, St Mary’s Hospice and St Giles Hospice forming the West Midlands End of Life Consortium.

Figure 2 – Connections between different providers in the West Midlands
Appendix 4

Hospice information

1 – Compton Hospice, Wolverhampton ✓ +
2 – Mary Stevens Hospice, Stourbridge
3 – Walsall Hospice, Walsall (under construction)
4 – Mary Ann Evans Hospice, Nuneaton
5 – Shakespeare Hospice, Stratford-upon-Avon
6 – St Richard’s Hospice, Worcester ✓ * +
7 – St Giles Hospice, Lichfield ✓ +
8 – St Giles Hospice, Sutton Coldfield ✓ +
9 – St Mary’s Hospice, Birmingham ✓ +
10 – Myton Hospice, Warwick
11 – Myton Hospice, Rugby
12 – Myton Hospice, Coventry
13 – Little Bloxwich Day Hospice, Walsall
14 – John Taylor Hospice, Birmingham
15 – Primrose Hospice, Bromsgrove
16 – Severn Hospice, Shrewsbury ✓ +
17 – Severn Hospice, Telford ✓ +
18 – Marie Curie Hospice, Solihull +
19 – St Michael’s Hospice, Hereford ✓ * +
20 – Katharine House Hospice, Stafford +
21 – Douglas Macmillan Hospice, Stoke-on-Trent ✓ * +
22 – Kemp Hospice, Kidderminster
23 – Sue Ryder Homecare, Wolverhampton
24 – Sue Ryder Homecare, Leek

Figure 3 – Hospice locations (✓ = offer dementia specific courses, * = offer dementia related courses, + = offer other relevant courses)
The coverage or catchment area for each hospice has been estimated from the information available on their websites, and is shown in the diagram below. Darker blue areas indicate parts of the region that are covered by more than one hospice. It should be noted that as these catchment areas are estimations, they may not be entirely accurate and may actually cover more of the areas that appear to be excluded.

Figure 4 – Approximate hospice coverage
<table>
<thead>
<tr>
<th>Hospice</th>
<th>Location</th>
<th>Population covered</th>
<th>In-patients</th>
<th>Day patients</th>
<th>Home care/ hospice at home</th>
<th>Dementia patients</th>
<th>Additional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compton</td>
<td>Wolverhampton</td>
<td>1,300,000</td>
<td>✓ 22 beds</td>
<td>✓ 20</td>
<td>✓</td>
<td></td>
<td>Part of West Midlands End of Life Consortium</td>
</tr>
<tr>
<td>Mary Stevens</td>
<td>Stourbridge</td>
<td></td>
<td>✓ 10 beds</td>
<td>✓ 15</td>
<td></td>
<td></td>
<td>Partially funded by Dudley PCT</td>
</tr>
<tr>
<td>Walsall</td>
<td>Walsall</td>
<td></td>
<td>✓ 12 beds</td>
<td>probably</td>
<td>✓</td>
<td></td>
<td>Still under construction, co-located with specialist dementia unit</td>
</tr>
<tr>
<td>Mary Ann Evans</td>
<td>Nuneaton</td>
<td>n/a</td>
<td>✓ 15</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shakespeare</td>
<td>Stratford-upon-Avon</td>
<td>120,000+</td>
<td>n/a</td>
<td>✓ 15</td>
<td>✓</td>
<td></td>
<td>(See ‘Additional’)</td>
</tr>
<tr>
<td>St Richard’s</td>
<td>Worcester</td>
<td>288,000</td>
<td>✓ 16 beds</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>St Giles (2 centres)</td>
<td>Lichfield &amp; Sutton Coldfield</td>
<td>600,000</td>
<td>✓ 18 beds</td>
<td>✓ 24</td>
<td>✓</td>
<td></td>
<td>Part of West Midlands End of Life Consortium</td>
</tr>
<tr>
<td>St Mary’s</td>
<td>Birmingham</td>
<td></td>
<td>✓ 25 beds</td>
<td>✓ 20</td>
<td>✓</td>
<td></td>
<td>Part of West Midlands End of Life Consortium</td>
</tr>
<tr>
<td>Myton (3 centres)</td>
<td>Warwick, Rugby &amp; Coventry</td>
<td></td>
<td>✓ 24 beds</td>
<td>✓ 15+</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little Bloxwich</td>
<td>Walsall</td>
<td>n/a</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>Run by Walsall PCT</td>
</tr>
<tr>
<td>John Taylor</td>
<td>Birmingham</td>
<td>400,000+</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓ only a few</td>
<td>Run by Birmingham East &amp; North PCT</td>
</tr>
<tr>
<td>Primrose</td>
<td>Bromsgrove</td>
<td>✓ 6 beds (See ‘Additional’)</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td>In-patient beds are at Princes of Wales Community Hospital</td>
</tr>
<tr>
<td>Hospice</td>
<td>Location</td>
<td>Population covered</td>
<td>In-patients</td>
<td>Day patients</td>
<td>Home care/hospice at home</td>
<td>Dementia patients</td>
<td>Additional</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------------------</td>
<td>--------------------</td>
<td>-------------</td>
<td>--------------</td>
<td>--------------------------</td>
<td>-------------------</td>
<td>------------------------------------------------</td>
</tr>
<tr>
<td>Severn (2 centres)</td>
<td>Shrewsbury &amp; Telford</td>
<td>2500/year</td>
<td>✅ 421 in-patients/year</td>
<td>✅</td>
<td>✅</td>
<td>Not normally</td>
<td></td>
</tr>
<tr>
<td>Marie Curie</td>
<td>Solihull</td>
<td></td>
<td>✅ 17 beds</td>
<td>✅</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
<tr>
<td>St Michael’s</td>
<td>Hereford</td>
<td></td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td>Not unless got other illness</td>
<td></td>
</tr>
<tr>
<td>Katharine House</td>
<td>Stafford</td>
<td></td>
<td>✅ 10 beds</td>
<td>✅ 15</td>
<td>✅</td>
<td></td>
<td>No educational unit</td>
</tr>
<tr>
<td>Douglas Macmillan</td>
<td>Stoke-on-Trent</td>
<td></td>
<td>✅ 28 beds</td>
<td>✅ 25</td>
<td>✅</td>
<td>&lt;10 out of 650 in-patients</td>
<td></td>
</tr>
<tr>
<td>Kemp</td>
<td>Kidderminster</td>
<td></td>
<td>n/a</td>
<td>✅ 15</td>
<td>✅</td>
<td>5 out of 45 patients</td>
<td>Will only take dementia patient if it is safe for them</td>
</tr>
<tr>
<td>Sue Ryder (2 centres)</td>
<td>Wolverhampton &amp; Leek</td>
<td></td>
<td>n/a</td>
<td>n/a</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Table 21 – Hospice information*