



Association for Dementia Studies

**Workforce Development for Dementia:
Development of role, competencies and
proposed training for; “Primary Care Liaison
Worker” to support pathway to diagnosis of
dementia**

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SUMMARY

This report was commissioned by the West Midlands Strategic Health Authority, to develop the role of a Primary Care Liaison worker focussing on the needs people pre-diagnosis with dementia. It was undertaken by the Association for Dementia Studies, University of Worcester from October 2009 to March 2010 and was based on an extensive review of the literature and a series of focus groups, interviews and written feedback from people living with dementia, their family care-givers and those working within the dementia care field. The concept for the Primary Care Liaison Worker originates from the West Midlands “*Darzi Dementia Care Pathway*” (Saad *et al*, 2008). Ensuring 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 is central to this. An informed and effective workforce for dementia is also Objective 13 of the National Dementia Strategy (DH, 2009).

Outcomes of report:

Development of a job description, person specification and related competencies for the Primary Care Liaison role

Recommendations:

- There is a need for a Primary Care Liaison role to be developed within primary care teams
- The role should be at a senior level as competencies identified require an experienced professional
- The role should be developed in partnership with Primary Care
- Should must have strong collaborate links with Specialist Mental Health services and the third sector
- A useful team model would be that the role is placed within a ‘GP cluster’
- Accessibility to GP records and collaborative working with GPs is essential within the role
- Personal continuing professional development (CPD) has a high profile in the role
- The role is supported by appropriate clinical supervision

Introduction

This report was compiled as a collaborative activity between the University of Worcester and Staffordshire University. It brings together two parallel but complementary streams of work: development of the role of (1) a Primary Care Liaison worker by the Association for Dementia Studies, University of Worcester, and (2) a Dementia Pathway Coordinator by the Centre for Ageing and Mental Health, Staffordshire University.

The scope of the project was to:

- 1) Develop job descriptions; person specifications;
 - 2) Develop competencies;
 - 3) Make recommendations for appropriate training/education programmes suitable to enable individuals to fulfil the above new roles in dementia care.
- The same project methodology was used by both teams to arrive at the recommendations presented here.

The National Picture

Dementia has become high profile over recent years, partly in response to the recognition that the older population in the United Kingdom (UK), and globally, is increasing (Dementia UK, 2007; Knapp *et al*, 2007), and also because of the associated health and social care costs (Alzheimer's Research Trust, 2010; Lowin *et al*, 2001). It has been acknowledged that dementia will present a challenge for services as the population ages. Alongside this is increasing public awareness of dementia and the expectation that increasing numbers of people will be seeking an early diagnosis (DH, 2009). Early diagnosis is known to significantly influence the quality of life for the individual and their families (DH, 2009). However, there are issues related to making an early diagnosis that indicate a need to approach this with sensitivity.

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 objective 13 of the

Strategy is to develop “*an informed and effective workforce for people with dementia*” (DH, 2009). Improving public and professional awareness and understanding of dementia is the first objective of the National Dementia Strategy (DH, 2009). This is an essential component within healthcare services in moving towards appropriate help-seeking and help provision early on. It is also recommended that health and social care managers should ensure 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-SCIE, 2007).

The West Midlands Darzi Dementia Pathway

The vision of the West Midlands “*Darzi Dementia Care Pathway*” (Saad *et al*, 2008) is to, by 2012 ensure that: “... *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*” (p, 5).

The report identified eight standards that are expected to help achieve the vision for the West Midlands. These are: jointly planned health and social care commissioning for people with dementia and their caregivers which provides seamless, integrated and proactive care; services for dementia interfaced with services available for all other long term conditions and those for older people; home as the base starting point for interventions; a competent workforce; resourced intimate caregiver service; a Dementia Pathway Co-ordinator; use of GP practices to trigger preventative and therapeutic actions for defined types of dementia; and minimum core standards of competency for dementia care used to underpin all education programmes for staff working with these people (Saad *et al*, 2008).

Saad *et al*, (2008) base the principles applicable across the whole dementia pathway on the document “*Putting People First*” (HM Government, 2007), which is a partnership between the whole of central government, local government, the NHS and the social care sector that aims to transform adult social care. This

work sets out clearly what needs to be achieved, stressing the need for improved information and advocacy and more control and personalisation of services. “Features of a good care pathway” (Figure 1), was developed by Saad *et al* (2008) and identifies where the role of a Primary Care Liaison Worker (highlighted below) could be positioned in relation to the pathway for persons with dementia, including pre-diagnosis of dementia. “The Mental Health and Vascular Risk Factor Wellbeing Service (50+): Integrated Service Care Pathway 2009” (Sharrock and Higginson 2008) was also used as a guide for positioning resources within primary care services regarding early detection of dementia for a recognised risk group.

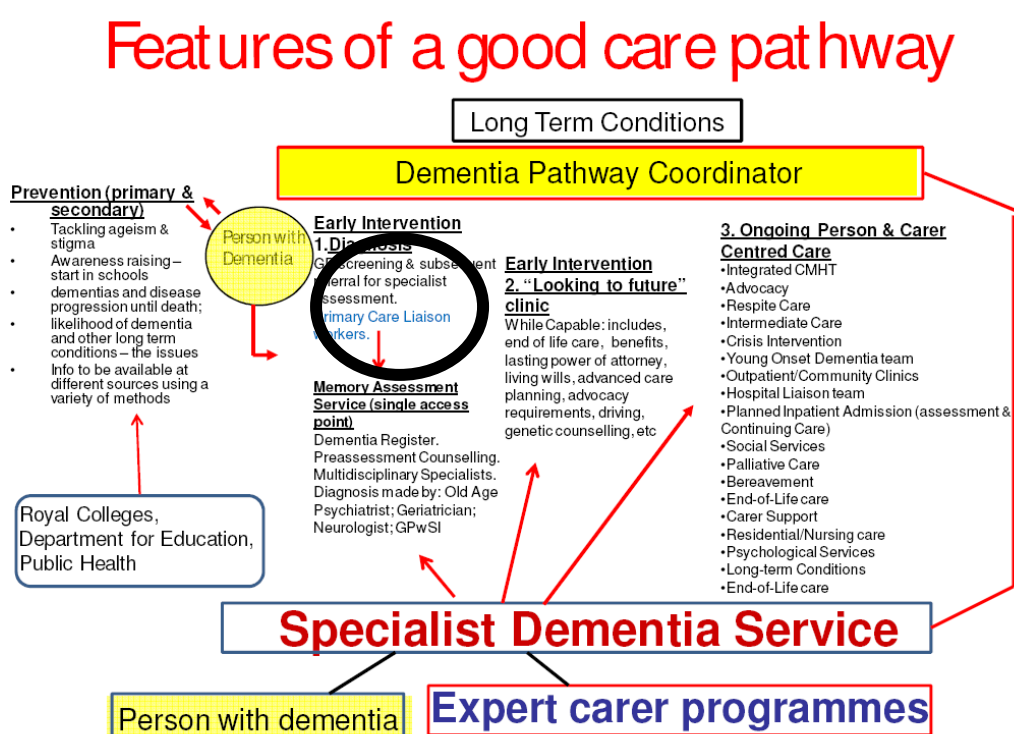


Figure 1 The West Midlands Darzi Dementia Care Pathway (Saad *et al*, 2008)

Project design and methodology

A project team was established and both work-plans and a time frame were agreed with the commissioning organisation.

Literature Review

Comprehensive literature and policy reviews were conducted relating to both roles. The key search terms for the Primary Care Liaison role were: dementia

and various combinations of the following terms: *liaison; community; primary care; stigma; awareness raising; screening; diagnosis; support; recruitment; education; skills; competencies*. The inclusion criteria included: English language journals; UK located was the preference but inclusive of relevant non-UK literature was used in the review; and dementia based. The exclusion criteria were: secondary or tertiary care literature. Databases searched included: Pubmed; Age-info; Social Care online; National Library for Health; PsychINFO; CINAHL; OVID Nursing Collection; Google Scholar; plus a wide range of 'grey literature' which included policy documents; relevant job descriptions, competencies and education programmes. The main search was conducted in January 2010, but was also ongoing over the period of the project. These reviews were used to establish draft competencies or different options/combinations of competencies and competency levels. (see Figure 2 for diagrammatic presentation of the process of consultation)

Consultation

The consultations with stakeholders fell into two main areas of work:

1. Consultations with professional stakeholders

This consultation involved:

- i. Stakeholder meetings at Staffordshire University and the University of Worcester
- ii. Widespread circulation of documents as the project proceeded to allow for stakeholders to respond electronically
- iii. Telephone conversations and meetings with interested parties.

Responses were collated and shared within the team in order to develop the work.

An initial group of relevant stakeholders were identified (including organisations which could offer feedback/links and representation of users and carers). Further groups of stakeholders were identified by the initial group. In all 14 stakeholders were consulted using focus groups, another nine were consulted electronically. They were representative of a large spectrum of the community environment and reflected service user needs and also the

requirements of professionals who were part of multidisciplinary and multi-agency teams. They included: GPs; health service commissioners; clinical psychologists; community matrons; Admiral nurses; social workers; and primary care project managers.

2. Consultations with users and carers

User and caregiver views were drawn from a range of sources: visits to user and carer groups such as Al's cafes; phone discussion with contacts; conference gatherings; internet 'chat' groups; 'Uniting Carers for dementia'; and contacts made through other links. Both roles were discussed with users and caregivers with cross-over feedback from the consultations carried out by colleagues at Staffordshire University. In all over 70 users and carers were consulted.

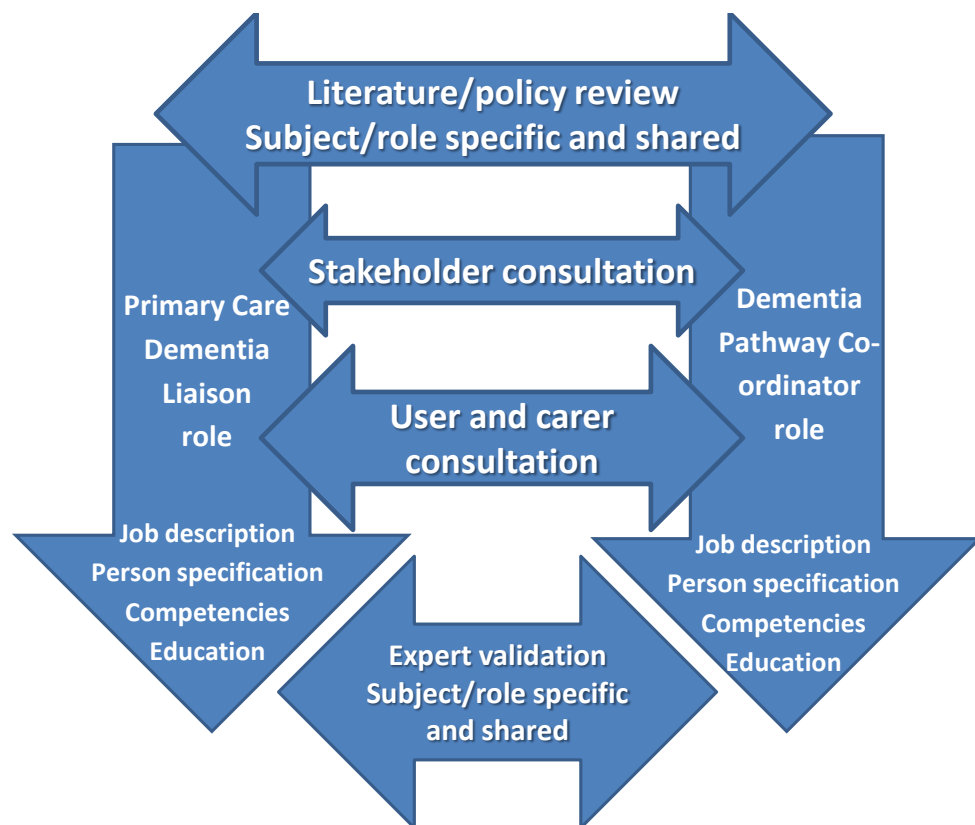


Figure 2 Consultation process

Competencies development

Draft competencies were developed based on the literature and policy documents including existing job descriptions for similar roles. In relation to the Primary Care Liaison role, comment on whether there was a gap in the services was also sought from stakeholders.

The draft competencies for both roles were distributed to all stakeholders who confirmed/expressed an interest in contributing to the consultation process. They were invited to attend a focus group to provide a consultancy role in validating the competencies, or to contribute electronically to the consultancy process. Following consultation, further drafts of competencies and role descriptions for both roles were developed. Those who had contributed to the first draft of the competencies were asked again to comment (electronically only). Finally, using the expertise of a smaller group of stakeholders, the competencies were validated. The final recommendations for job descriptions; person specifications; competencies and recommended training and education, are presented here.

Equality of Impact Assessment

In order to address the requirements regarding equality issues in developing the competencies for the roles, the potential impact on minority groups needed to be taken into account. Therefore an Equality Impact Assessment (EqIA) (DH, 2008) was conducted (see Appendix 1). Consultation with users also contributed to the construction of the EqIA report. The EqIA was specifically aimed at consultation with 'hard-to-reach' groups in relation to dementia care and the development of both roles.

What is the Primary Care Liaison worker role?

The role of the Primary Care Liaison Worker, according to Saad *et al*, (2008), would enable a person with suspected dementia to access an assessment process directly and with expediency. It was envisaged that the person in this role would be in a position to assist GPs to help their patients access Memory Assessment Services and would be able to work across a number of practices.

"The 'Worker' who will be trained in triaging for the disorder and a knowledge of local Dementia services, will arrange the necessary examination/dementia blood and urine screen to take place, and swiftly facilitate access to the Memory Assessment Service. This process may facilitate access to assessments in certain complex situations which may otherwise lead to unnecessary delays in obtaining a diagnosis e.g. when there may be a reluctance to convince the person with suspected Dementia to attend for tests." (Saad et al, 2008 p25).

Although they do not specifically refer to the Primary Care Liaison Worker role as encompassing the responsibility of conducting pre-assessment counselling, (Saad et al, 2008, p25) proposed that:

"This (pre-assessment counselling) should be available to enable people to make an informed decision whether to proceed to having a memory assessment. Information about the process and its implications will be made available. Any information deemed helpful to the assessment process may be communicated to the specialist team provided there is valid consent to do so." (Saad et al, 2009, p25).

Consequently, it was decided that the *intention* of the Dementia Clinical Pathway Group (Saad et al, 2008) was that the Primary Care Liaison role *should* include competencies for pre-diagnostic counselling and *may* include competencies for pre-diagnostic screening. Pre-diagnostic screening is proposed as an extended role option within the competencies (see appendix 2).

The background literature is discussed followed by the outcome of the consultancy presented against each of the competencies that were identified and validated by stakeholders and users.

Literature review

Raising awareness and reducing stigma

Historically dementia has suffered from poor awareness and understanding, combined with the stigmas attached to both mental illness and old age. The stigma attached to dementia may put people off seeking a diagnosis (National Audit Office, 2007). Fears include loss of: autonomy; sense of control; self-

esteem; competency; valued lifestyles; social roles; relationships; and one of the most feared losses in dementia is the loss of sense of identity (Aminzadeh *et al*, 2007). The stigma of a diagnosis of dementia causes complex emotional responses. For example Aminzadeh *et al*, (2007) show how people went through stages of emotional response to their diagnosis from: not noticing symptoms, noticing and covering up, or noticing and revealing; diagnostic process and disclosure; confirming or shock; denial, crisis, or maximising; disorganisation or adaptation.

A survey commissioned by Bupa Care Services has shown that 58% of people over the age of 55 listed dementia as their biggest concern, over becoming physically frail (51%) and cancer (49%) (Hunt, 2009). Not only do people who are diagnosed with dementia have to cope with the losses associated with a disabling and terminal disease, but also have to face the stigma attached to the diagnostic label (Harman and Clare, 2006). There are also reports of the negative impact of non-disclosure or the provision of a vague diagnosis, resulting in confusion and emotional distress (Bamford *et al*, 2004; Wilkinson and Milne, 2003). Also people may be aware that something is wrong but are not able to confirm this and are isolated in their uncertainty (Clare, 2003).

Screening for dementia

Both simple screening tools and advanced memory clinics do not ensure dementia detection in primary care (Perry *et al*, 2008) and early screening and detection of dementia in primary care remains controversial (Boustani *et al*, 2006). At least half of the patients identified as cognitively impaired by screening instruments do not meet criteria for a dementia diagnosis and some patients refuse further evaluation following a positive screen. The reason for high refusal is suggested by Boustani *et al* (2003, 2006) to be related to perceived harms of having a dementia diagnosis. Also lack of a cure for Alzheimer's disease and the belief that little can be done for someone with Alzheimer's disease are frequently endorsed barriers to proceeding to diagnosis (Connell *et al*, 2009).

Boustani *et al* (2008) developed, pilot tested and validated a questionnaire that captured patients' attitudes about dementia screening in primary care in the

USA, the 'Perceptions Regarding Investigational Screening for Memory in Primary Care' (PRISM-PC) questionnaire. It captures primary care patients' acceptance, perceived harms, and perceived benefits of dementia screening. The PRISM-PC questionnaire revealed that patients do perceive harm in having a dementia diagnosis, particularly related to loss of health insurance coverage, driver privileges, and employment positions. It did reveal some positive non-medical consequences of screening for dementia, namely having more time to plan for the future, and more time for overall family discussions and planning (Boustani *et al*, 2008). Findings supported by Bamford *et al*, (2004) and Wilkinson and Milne, (2003), specifically confirmation of suspicion, sense of relief, opportunity to develop positive coping skills, and chance to make most of time.

Replication of the PRISM-PC questionnaire in the UK by Justiss *et al* (2009), revealed similar findings to those of Boustani *et al* (2008). Specifically UK participants were more accepting of dementia screening, however, despite this the UK group considered a diagnosis of dementia to carry more stigma, and greater impact on independence and suffering (Justiss *et al*, 2009). Both the US and UK participants had similar responses to the perceived benefits of dementia screening and prior experience with dementia impacted the acceptance score between the groups (Justiss *et al*, 2009). Furthermore screening tools need to be: cheap; acceptable to users and clinicians; brief and easy to administer, score and interpret; validated in a community, population or primary care sample; and with high sensitivity and specificity (Brodaty *et al*, 2002; Brodaty *et al*, 2006).

Mild cognitive impairment

Increasing attention is being paid to persons with mild cognitive impairment for whom treatment options are being evaluated that may alter the rate of progression to dementia (Petersen *et al*, 2001). However, the concept and classification of MCI is debated at length within the literature (Hodson and Keady, 2008; Steenland *et al*, 2008; Stephan *et al*, 2008), and is disputed by some, for example Whitehouse and Moody (2006), who claim that MCI has no clinical relevance. However, guidelines propose that professionals in primary care should refer people with signs of MCI for assessment to memory services (NICE

SCIE, 2007). The drive behind exploring MCI is due to an earlier potential point for therapeutic intervention (Hodson and Keady, 2008).

Diagnosis of dementia

Concern over delay in the diagnosis of dementia within primary care has been expressed for the last 40 years (Bamford *et al*, 2004) and is a frequently expressed concern of caregivers of people with dementia (Bamford *et al*, 2007). Also the lack of formal diagnosis even for those who are experiencing significant cognitive loss remains a significant problem for people living in the community (Brooker *et al*, 2009a). Perry *et al* (2008) report on several American and European studies that have shown the 50% or more of people with dementia are not diagnosed (Löppönen *et al*, 2003; Valcour *et al*, 2000; Wilkins *et al*, 2007). Only one third of people with dementia in the UK are ever formally diagnosis (National Audit Office, 2007; Banerjee and Chan, 2008; House of Commons Committee of Public Accounts, 2008 Waldemar *et al*, 2007). Diagnosis and contact, when made, often only occurs late in the illness and in crisis when opportunities for harm prevention and therapeutic intervention are limited (Dening and Milne, 2008). Waldemar *et al* (2007) highlight the importance of policy makers and authorities being made aware of the benefits of early access to diagnosis and treatment.

Even with the development of guidelines, improvement in diagnosis has been slow. Waldorff *et al* (2003) found little change in adherence to guideline recommendations regarding laboratory tests or cognitive tests in diagnostic evaluation in Denmark, a finding consistent with UK practices (Turner *et al*, 2004).

The pivotal role of the GP in the early identification, possible diagnosis/referral to Memory Services and subsequent management of dementia has long been recognized (Iliffe *et al*, 2006; Iliffe *et al*, 2003; Woods *et al*, 2003; Iliffe and Wilcock, 2005) and whilst diagnostic practice is improving, the knowledge gained from research exploring the patient perspective is insufficiently absorbed into practice (Wilkinson and Milne, 2003). Turner *et al* (2004) found that one third of general practitioners expressed limited confidence in their diagnostic skills, whilst two-

thirds lacked confidence in management of behaviour and other problems in dementia. Also information about management processes are not well evidenced in primary care records (Wilcock *et al*, 2009).

It is proposed that 'timely' rather than 'early' diagnosis was more appropriate in conjunction with a strong infrastructure of multidisciplinary collaboration (Lepeleire *et al*, 2008; Vernooij-Dassen *et al*, 2005; Waldemar *et al*, 2007).

However, UK GP attitudes to their involvement in making a dementia diagnosis were found to be underpinned by drivers and barriers and those GPs who were committed regarded it as an opportunity to offer preventive treatment and plan for the future. However some of the barriers included limited treatment options (Milne *et al*, 2005).

Using data from a self-administered questionnaire from 278 GPs in Scotland at the outset of a two-hour training seminar on dementia, Downs *et al*, (2000) found once dementia is suspected, unlike their Australian counterparts, a significant percentage of GPs neither conducted medical tests to exclude underlying treatable causes nor assessed for depression. Few GPs referred people with dementia and their families to dementia services. There is no evidence that this state of affairs has improved since 2000 and as Cahill *et al* (2008) highlight, health professionals who fail to investigate patients presenting with dementia symptoms can delay diagnosis, denying patients and caregivers early intervention that could improve quality of life for both patient and caregiver.

Impact of diagnosis

A diagnosis is required prior to introducing interventions in the care of persons with dementia. Early intervention has been shown to have a positive effect on the quality of life for people with dementia (Banerjee *et al*, 2007) and on their family carers (Mittleman *et al*, 2007) and a wider commitment to early intervention, particularly in primary care, is a prerequisite of promoting psychosocial well being amongst people with dementia (Milne and Peet 2008).

It is also recognised that there is an economic benefit for healthcare services related to early diagnosis enabling more to be done to delay progression of the

disease and impacting on admission to acute and other healthcare environments (National Audit Office, 2007). Having a clear diagnosis can also reduce the number/length of acute hospital episodes and delay the need for admission to more expensive long-term care (National audit Office, 2007; Brooker *et al*, 2009b). Banerjee and Wittenberg (2009) analysed the cost benefits of commissioning memory services for early diagnosis and intervention for dementia. They concluded that the service only needs to achieve a modest increase in average quality of life for people with dementia, plus a 10% diversion of people with dementia from residential care to be cost-effective and discuss significance of this approach in relation to providing, planning and commissioning dementia services.

Diagnostic disclosure in dementia is both inconsistent and limited with the perspectives of the people with dementia being largely neglected (Bamford *et al* 2004). Also studies in the US have shown that people with dementia who were older and lived alone were less likely to be diagnosed (Wilkins *et al* 2007). The process of making a diagnosis of dementia is a multidisciplinary/ multiagency shared responsibility (Iliffe *et al* 2009). Milne and Peet (2008) identified this as a key recommendation following their systematic review; *"disclosure needs to be embedded within a diagnostic process, one that is managed in an unhurried empathetic manner. The timing of disclosure is very important; users and carers need to be 'primed' and given time to react, ask questions, and consider future challenges"*. Disclosure of a diagnosis is just the beginning of the experience for people with dementia and their significant others and they will return again and again (with family members) for clarification and detail. This needs to be managed in an unhurried empathetic manner (Milne and Peet 2008).

Comprehensive guidelines for the diagnosis and management of dementia have been developed by NICE SCIE (2007) with recommendations that a diagnosis of dementia and dementia subtypes should be made by a healthcare professional with expertise in differential diagnosis using international standardised criteria, a comprehensive assessment approach; and appropriate diagnostic tools (NICE SCIE, 2007). From 2006-07, UK GPs have been given financial incentives to record and monitor people with dementia by keeping a register of dementia

patients and reviewing each case every 15 months. The National Audit Office, (2007) survey found that 67% of GPs said they had a register and 79% reported that it prompted them to review cases, though types of review varied widely. Seventy per cent of GPs said a lack of time during surgery visits prevented them doing as much as they would like for people with dementia.

However, GP registers are not accessible to others in the system such as the ambulance service, A&E or mental health trust professionals. Patient records are currently not accessible to other professionals outside the GP practice, making coordination of care difficult (National Audit Office, 2007). Iliffe *et al*, (2006) found that resistance to shared care mostly came from within general practice reflecting concerns about staffing, time constraints, lack of experience and confidence in making and disclosing a diagnosis. The authors found that the core issue for practitioners was resources i.e. the availability of personnel and time to respond to patients and their significant others who have with concerns or anxieties regarding the possibility of having dementia. The review by Milne and Peet (2008) found that users and carers need to be able to return to a single point of contact to follow up concerns, gather more information, seek advice and receive support. This needs to take account of the user's approach to coping, and their capacity to adjust to change (Milne and Peet, 2008).

Identified need for post

There was no doubt, from the literature, that there is a very real need to find means of increasing diagnosis for people with dementia, and the stakeholder consultation repeatedly affirmed that without a diagnosis the person with dementia and their caregivers did not get access to the appropriate services, i.e. medication for cholinesterase inhibitors, support services etc. The importance of early and accurate diagnosis and intervention was emphasised by all stakeholders and users during the consultation.

"I am saying that early diagnosis is the only thing that gives you a ticket to the ball".
The consultation with stakeholders validated the need for a role that would be able to improve a system that would deliver an early and 'timely' diagnosis, but just how this could be facilitated was a matter of debate. There was a great deal

of discussion on how a dementia pathway should 'look' and where in the pathway particular professionals should/could be positioned and clearly some confusion amongst stakeholders regarding the difference between the Primary Care Liaison role and that of the Dementia Pathway Co-ordinator role, with stakeholders questioning whether there was a the need for two new roles rather than only one. Stakeholders were also concerned that the general public could become confused about the two different roles. Particularly, when following diagnosis, how the transition from the Primary Care Liaison worker to the Dementia Pathway coordinator would be managed by the teams.

At times the responses were overwhelmed by the repeatedly expressed concern regarding funding i.e. negative expression regarding lack of funding to establish such a role; questions such as, "*would there be any funds available for such a post?*", and the complexities and difficulties for commissioners to allocate finances to services equitably. In dealing with the issues of funding there was a general consensus amongst stakeholders that a priority was first and foremost "*up-skilling*" of existing primary care staff across all professions. This is an acknowledged and valid concern, however, under the requirements of the consultancy this was not the brief so these concerns are not addressed in this report.

Users, specifically and repeatedly reported on issues and experiences regarding how their diagnosis was managed by the primary care services, reporting, in the main, negative experiences, although there were also some very positive experiences. Caregivers reported that they found there were so many organisations out there that they didn't know where to turn for advice (before and after diagnosis). They become confused about services and at the same time were also dealing with the distress of having a potential or confirmed diagnosis. They saw their GP as the central professional to consult and the greatest need identified by users was easier access to, and continuity of, services. There was particular concern voiced regarding seeing a different professional at each visit to Memory Services for a number of caregivers.

Overall, responses from both stakeholders and user/caregivers supported the key recommendations made by Milne and Peet (2008) and guidelines developed by NICE SCIE, (2007). Therefore the development of the role of a Primary Care Liaison role may be viewed as timely and as a role that may significantly contribute to engaging in collaborative approaches to dementia care within primary care. A person taking on this new role will need to work closely with other members of the multidisciplinary and multi-agency teams, particularly in relation to the sensitivity and complexity of dealing with pre-diagnostic screening for dementia and the emotional turmoil that this may engender.

Competencies for the Primary Care Liaison role

The full set of competencies and job description can be found in appendices 2 and 3 respectively. In summary, the following competencies (and associated skills) were identified as essential for the Primary Care Liaison role:

- 1) Knowledge/awareness of dementia and dementia related issues;
- 2) Comprehensive understanding of the behaviours of individuals with early cognitive impairment, dementia and other illnesses that have a neuropathology;
- 3) Skilled in interacting with people with wide range of illnesses including mild cognitive impairment and dementia;
- 4) Skilled in interacting with families and or significant others of people at risk or with concerns about dementia; education/facilitation and information giving;
- 5) Competent at providing education/facilitation and giving information to families and caregivers
- 6) Skilled in conducting pre-diagnostic screening for people who are have anxieties/concerns about dementia symptoms;
- 7) Personal qualities

The following provides the background to how these competencies were supported by the stakeholders and literature.

Competency 1. Knowledge/awareness of dementia and dementia related issues

A Primary Care Liaison role would require a person with sound academic and up-to-date research and clinical knowledge of pathophysiology of dementia syndromes and the relationships between dementia and other pathologies as well as a high level of knowledge of all services related to dementia. There was confirmation by stakeholders that such a role would require a person to have a comprehensive knowledge and understanding of dementia and dementia related issues.

A competency requiring knowledge and awareness of dementia is fundamental for all level of people working within the healthcare arena (DH, 2009), however, in relation to the Primary Care Liaison role the level of skills within the competency were deemed to be of a highly professional standard. Stakeholders identified the following group as suitable professionals to undertake such a role if they were suitably qualified and experienced: *clinical psychologist; old age psychiatrist; geriatrician; general practitioner; mental health nurse; occupational therapist; mental health social worker; general nurse.*

Also, it was important that the competencies and skills of a person in this role had the professional and clinical respect of all members of the team, particularly that of the GP (La Fontaine and Whitehouse 2001). This was highlighted during the focus group discussions. *“One of the things that struck me was that it didn't have to be nurses doing that job; we employed a social worker who did it just as well. The issue is not about profession, it's about competence, experience, understanding, their sensitivity, their capacity to influence others. The reality was that GPs would not listen to people that were not qualified – as they perceived it. Now that was ten years ago, it may be different now, but at the time there was a real sense of ‘what are you in here for? Go away and don't bother me’ if they didn't have the capacity to garner attention through your experience and your capacity to persuade the GP or the Practice Nurse or the District Nurse. That's not about type of professional, but it is about experience, skill, and competence”.*

Consequently, all following competencies are identified as being in keeping with a professional level at least at band 7. This set the scene for the job description, person specification, competencies and related skills that were developed.

Competency 2. Comprehensive understanding of the behaviours of individuals with early cognitive impairment, dementia and other illness that have a neuropathology

The skills required within this competency focus on advanced awareness of the impact of the fear and stigma of a dementia diagnosis and of potential losses associated with a diagnosis of dementia, of barriers to diagnosis and reasons why people may not want to proceed to a formal diagnosis.

This competency engendered intense discussion and debate particularly regarding MCI. There was cohesion within stakeholder groups and electronic feedback that this was a factor that could not be overlooked but required sensitivity and a highly skilled clinician to engage in discussions with patients and their families regarding assessment, information giving and possibly referral for diagnosis of dementia. Ethical implications of pre-diagnostic screening for dementia was highlighted as an important consideration within the role by a number of stakeholders.

Pre-diagnosis screening would require a professional to work at a high level of complexity and to be sensitive to the emotional responses to both a possible diagnosis and a confirmed diagnosis of dementia. Boustani *et al* (2006, 2008) is adamant in stating that it is also essential for healthcare professionals to improve their understanding of the decision-making process driving patients' beliefs and behaviours about the benefits and risks of dementia screening and diagnosis before implementing any broad-based initiatives for dementia. The consultation for this project concluded that undertaking these discussions with patients and their significant others should be conducted by a very highly skilled practitioner.

Competency 3. Skilled in interacting with people with wide range of illnesses including mild cognitive impairment and dementia

This competency is interrelated to competency 2 above but specifically relates to the need for a person in such a role to have counselling skills, advanced communication skills and be skilled in breaking or 'endorsing' bad news. For example; the ability to find out what the patient already knows or suspects about their diagnosis; using the actual words "dementia" or "Alzheimer's disease" when talking to the patient (i.e. the use of explicit terminology); exploring what a possible diagnosis means to the patient. The need for skills in counseling within the role is emphasised by Saad *et al*, (2008, p25) "... when there may be a reluctance to convince the person with suspected Dementia to attend for tests."

Stakeholders were unanimous regarding the importance of the Primary Care Liaison role being integral to multidisciplinary and multiagency working and saw the GP as having pivotal role in the process of pre-diagnosis screening and diagnosis of dementia.

This stigma of dementia, and concerns regarding working with marginalised groups was discussed by stakeholders. It was supported that one of the competencies required was skill and experience in working with 'hard to reach' groups. The list of people who may be considered 'hard to reach' in terms of healthcare needs and interventions group is not exhaustive. (see EqIA appendix 1 for more detailed discussion on this).

Competency 4. Skilled in interacting with families and or significant others of people at risk or with concerns about dementia

This competency is closely related to competencies 2 and 3 above.

Understanding the importance of relationships was seen as essential by users and caregivers. The person in the role would need to have sound knowledge of the significance of relationships when interacting with family members as relationships are central in the care-giving process (Askham *et al*, 2007; Forbat, 2003; Henderson and Forbat, 2002). Relationships can provide insights into care exchanges and embedded in this approach is that the accounts of the person

with dementia is taken seriously (Bamford *et al* 2004; Forbat, 2003; Wilkinson and Milne, 2003). Users and caregivers particularly focused on the importance of families and relationships, with much more emphasis than did the stakeholders, although stakeholders upheld the importance of establishing good working relationships with families and caregivers.

Competency 5. Competent at providing education/facilitation and giving information to families and caregivers

The skill requirements within this competency would be an expectation of any professional working at the recommended level for the role (DH, 2009). There is widespread ignorance and misrepresentations about dementia, both in the public arena and within healthcare environments. Raising awareness and reducing stigma are at the forefront of National Dementia Strategy (DH 2009) and working at raising awareness would be an essential component of the Primary Care Liaison role. Skills required would include experience and confidence in presentation and teaching for a wide range of audiences, e.g. general public; caregivers; school children; professionals etc.

Competency 6. Skilled in conducting pre-diagnostic screening for people who are have anxieties/concerns about dementia symptoms

This competency produced the most controversy and some heated debate within stakeholder discussions, particularly regarding which professionals would be experienced enough or qualified to conduct screening. This confirmed that the issue of routinely screening older people for cognitive impairment is controversial, if identifying those patients whose impairment is due to dementia can be justified, and the issue of who should undertake this screening has yet to be resolved (Boustani *et al* 2006). As one of the stakeholder's response indicated:

“‘Timely’ recognition (and diagnosis of dementia sub-type) implies that the recognition (or diagnosis) comes at the right time for the person and/or those around them. Part of the problem we have at the moment is that there is ample scope for misattribution of the early features of dementia syndrome, even when there are ample concerns expressed by family members. Putting that right will bring the point of recognition (or diagnosis) forward in time, so ‘timely’ diagnoses will be earlier. What I think we should avoid is

responding to dementia when those with it (especially families, but also individuals) have yet to recognise it".

Responses from users and caregivers upheld the need for development of screening processes pre-diagnosis of dementia. There were examples from caregivers of their family members having been given a 'diagnosis' of Alzheimer's disease by their GP that was later changed to a diagnosis of vascular dementia and the confusion this caused for the person with dementia and the family members. The average time, from suspicion of the possibility of dementia to diagnosis, reported by caregivers during this consultancy was between four and five years. Stakeholders in the focus groups reported that this time period is now more like 18 months, but this view is not upheld within the literature (Löppönen *et al*, 2003; National Audit Office, 2007; Perry *et al*, 2008; Valcour *et al*, 2000; Wilkins *et al*, 2007; Waldemar *et al*, 2007).

The role, as identified by Saad *et al*, (2008), proposes introducing a triage process. Consequently, this competency required skills in the use of relevant pre-diagnostic tools for dementia screening, skills in 'triage' processes and the ability to develop 'triage' tools specific to the area of pre-diagnosis screening for dementia. Triage, by definition, requires assessment instruments and this approach is historically located within emergency services. There were no examples of triage instruments/protocols within the literature that were specifically designed for the pre-diagnostic assessment for dementia.

Mental health triage systems developed in Australia (Broadbent *et al*, 2007; Sand, 2007) and Canada (Coristine *et al*, 2007) provide possible models that could be used for this role. In the Sand (2007) model the mental health triage clinician receives a referral from a primary care source, he/she then acts on the referral by, first, conducting a mental health assessment either by telephone and/or face-to-face, forming a provisional diagnosis, and then making clinical decisions related to the type of service or assistance required by the consumer. Referrals to the triage clinician are prioritised according to urgency, with the most acute or at-risk presentations acted on first. Within this model (and all other triage models) there is the expectation that the practitioner or triage clinician has

advanced skills in assessment, pre-diagnosis and decision making, and works to a specified protocol. Triage can also be regarded as a process in which nurses act as an adjudicating panel, judging the clinical data through appraisal of the way patients act out their problems and narrate their stories (Edwards and Sines, 2007).

Stakeholders also supported finding or developing the 'ideal' instrument. This should be one that is accessible to, and easily used by, both doctors and nurses (Iliffe and Manthorpe, 2004). As identified in the literature, much of the research on developing new screening processes and instruments diagnosis of dementia has been developed in the US. Skills in conducting practice evaluations and audit at an advanced level is recommended as part of taking forward developments in testing and validating screening instruments for pre-diagnosis of dementia and placing them within a UK context

Whilst it is envisaged that at diagnosis the person would be referred on to the Dementia Pathway Co-ordinator, this process must be streamlined and if a relationship has been established between the Primary Care Liaison worker and the person with dementia and their caregiver, the transition period would need to be managed sensitively. The diagnosis of dementia marks an important transition from uncertainty and ambiguity of the early cognitive and behavioural change to a phase in which the person adjusts and learns to live with the impairment (Woods *et al*, 2003) and as pointed out by stakeholders, this is the only path to becoming eligible for a range of services.

Based on the call for wider commitment to early intervention (DH, 2008; Milne and Peet, 2008), continued consultancy with 'experts', and on the related literature we recommend that this competency be given high priority in the development of the Primary Care Liaison role.

Competency 7. Personal qualities

Stakeholders and users (upheld by the literature) were unanimous in supporting a competency that called for a person skilled in person-centred care (Kitwood,

1997; Brooker, 2007). Personal attributes of empathy and warmth and genuineness were seen as important.

A matter of some discussion with stakeholders was the recruitment processes that should be used for the role. Recommendations from the stakeholders were that competency testing type approaches should be used (see job description appendix 3). It was also suggested that both a user (person with dementia) and a caregiver should be members of an interview panel for this type of position.

Considerations on how the Primary Care Liaison role should work

This role is primarily a 'liaison' role and liaison, by definition, means communication between different groups or units of an organisation; a person who initiates and maintains such a contact or connection. Based on this definition the development of the job description, person specification and competencies may have gone beyond the brief. However, this is a 'new' role, in-so-much as there has not been a position within primary care of this type to date. Consequently the consultation started with a 'clean slate'.

Where the person in such a role would be positioned was a matter of some debate amongst stakeholders. For the Community Matrons who were consulted the GP surgery was deemed a suitable site, however they indicated that just to be able to consult with 'someone' for advice on screening, even by telephone, would be what they would want from the role. A number of stakeholders recommended that the role be placed within a 'GP cluster', a model already in place in the pilot project in Stoke on Trent Primary Care Trust (NHS Stoke on Trent, 2010).

An evaluation of a Multi-Agency Training Project (La Fontaine and Whitehouse, 2001) demonstrated that there are key characteristics required of an individual professional who functions in a liaison role. These characteristics are less about the type of professional (e.g. nurse, psychologist or social worker) and more about the specific skills, knowledge and attitudes that are necessary. They identify 4 key characteristics of such a role:

- 1) The need for someone who can act as a consultant/advisor
- 2) To be an assessor
- 3) To act as a liaison agent
- 4) To be a therapist.

These four characteristics were confirmed by stakeholders as essential for the current role. Stakeholders had indicated a number of professionals who would be capable of performing the role of a Primary Care Liaison worker (see above **Competency 1**). Job descriptions, person specifications and competencies of posts of: social workers; occupational therapists; health visitors, public health nurses, mental health nurses, practice nurses and Admiral nurses were reviewed. Those designed for nursing roles were found to be the most appropriate/useful in gaining insight into the responsibilities and skills required for this new role. Competencies were drawn primarily from these positions using web-based searches for job descriptions, person specifications and competencies, primarily within the UK, although documents from North America and Australia were also made a useful contribution to the development of these.

Historically health visitors would have been in the position to take services forward in relation to working within GP clusters and screening for dementia in the old age group (Chew *et al*, 1994; Koch and Iliffe, 2009; Trickey *et al*, 2000). However, health visitors are now completely focused on children and young person services. This loss of the health visitor role was highlighted during the stakeholder discussions. *"What is the lost opportunity in the Health Visitor role? The Health Visitor was exceptionally good and took to the role like a duck to water and did tremendously well, the advantage of someone within the primary healthcare team or community team is someone as a true facilitator, already working within the team, and a single point of access for all the services"* (FG 1). However, there are a number of Primary Care Trusts, throughout the UK, who now employ 'Nurse Advisors for Older People'. Following the National Service Framework for Older People (DH 2001) these nurses are conducting the equivalent of the Over-75 Check, and in many cases are including pre-diagnostic screening for dementia.

The development of the job description, person specification and competencies for this role has also been influenced by existing UK models regarding pre-diagnostic screening for dementia. UK models of pathways that have been established within a primary care general practice appear to be providing a more holistic service to the screening, diagnosis and management of dementia (Koch and Iliffe, 2009; Brooke and Bullock, 1999; Brooke *et al*, 2005). Figure 3 outlines how the Primary Care Liaison role could be positioned based on successful existing services within the West Midland and on input from stakeholders. The Gnosall model identified health visitors (highlighted section below) performing the role we suggest would be that of the new role of Primary Care Liaison worker.

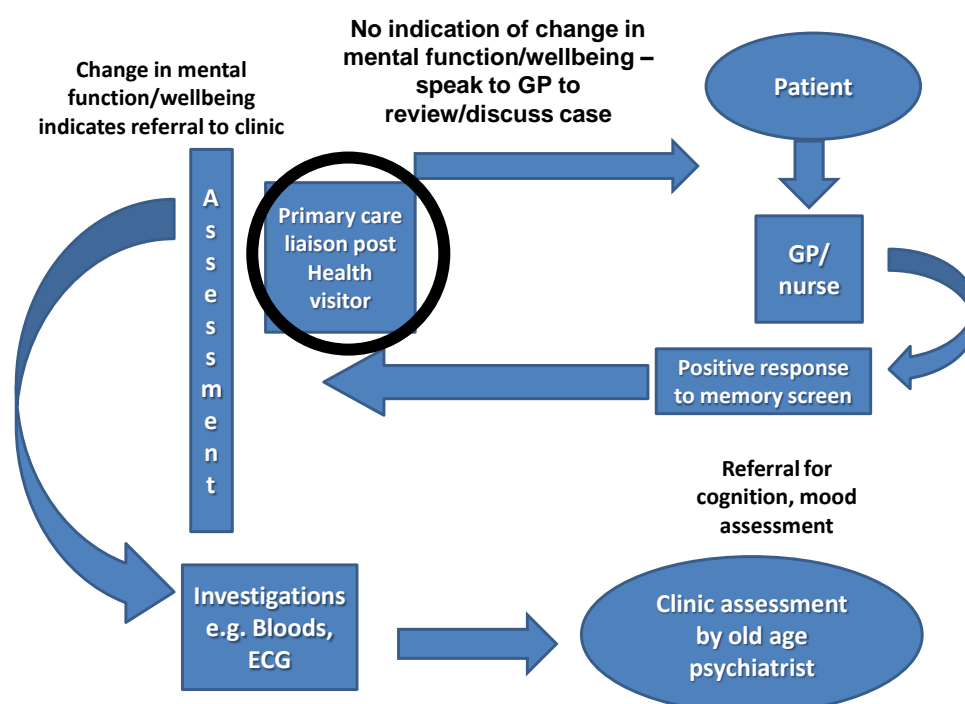


Figure 3. Adapted from “The Gnosall Hearts & Brains Clinic Care Pathway” (Koch and Iliffe, 2009)

As indicated in the Gnosall model (Koch and Iliffe, 2009), historically, when carrying out the Over-75 Check, health visitors were in a position to conduct preliminary screening of older people for a variety of disorders amongst which was dementia. The 1990 contract requires GPs to offer all their patients aged 75 years and over an annual health check. The contract specifies that the patients

should receive a written invitation, and it also specifies the areas to be covered by the assessment: sensory function, mobility, mental condition, physical condition, social environment and medication.

GPs are not obliged to carry this out personally and monitoring of take-up is not obligatory. In a seminal study conducted by Chew *et al*, (1994) it was found that many GPs pass on the responsibility for this service to other members of their practice team, and it was noted that in many cases it was undertaken by the practice nurse who may have had little or no relevant training. There was considerable variation in skills and autonomy amongst these professionals, with more highly trained nurses such as health visitors displaying more confidence and autonomy (Chew *et al*, 1994). The few evaluations that have been conducted on the Over-75 Check have demonstrated the potential benefits of the checks and also identify need for training for the nurses who are conducting these (Brown *et al*, 1992; Iliffe *et al*, 1991; Tremellen, 1992; Trickey *et al*, 2000).

The guideline should prompt professionals carrying out an Over-75 Check to recognize symptoms of dementia and raise awareness of the range of tasks which need to be undertaken in confirming diagnosis, assessing needs and managing patients. However, the literature revealed very little research or evaluation of the Over 75 Check when this is one of the most valuable and cost-effectiveness opportunities for establishing a screening system for pre-diagnosis of dementia and offers an offer an opportunity to discuss dementia in a routine way and reduce the associated stigma..

Trickey *et al* (2000), again in seminal work, conducted a survey of 382 GPs (and those other than the GP who conducted the Over-75 Check, i.e. practice nurses, health visitors, district nurses, unidentified 'others'), working in 209 practices in the UK. Results from this study suggest that improved training and increased autonomy for primary care nurses would improve access to services for these patients and their carers (Trickey *et al*, 2000).

As early as the mid 1990s it was shown that, given the increasing aged population and expectation of increased dementia diagnosis, the ability for GPs

to continue to be the main avenue of screening prior to diagnosis will be very limited (Trickery *et al*, 2000; Brodaty *et al*, 1998; Seymour *et al*, 1994; Chew *et al*, 1994). Chew *et al* (1994) suggest that, where adequately trained, nursing staff are able to carry out screening for cognitive impairment. The Over-75 Check being identified as one occasion where primary care nursing staff (generally health visitors, district nurses or practice nurses) have an opportunity to screen patients for cognitive impairment and to provide early intervention. However, an appropriate referral appeared to be more often the result of luck rather than judgement and vulnerable patients, such as those in poor health or who lived alone, were less likely to know about the health checks than other patients (Chew *et al*, 1994). As Trickery *et al* (2000) also found, the skills and expertise of the nurses were extremely variable and suggest that improved training and increased autonomy for primary care nurses would improve access to services for these patients and their caregivers, thus supporting the principles outlined here for the role of a Primary Care Liaison worker.

The Integrated Service Care Pathway 2009 (Sharrock and Higginson 2008) which addresses assessment of at-risk (for dementia) groups also provides a useful model of how the Primary Care Liaison role could be developed. The Service Pathway from Stage 1- 3 is similar to protocols for models developed within health visiting services (DH, 2007) and also some triage models..

Stage 1 – recognition and identification of target population using ‘alerter referral decision making tool’;

Stage 2 – assessment formulation (functional analysis, screening, differential diagnosis);

Stage 3 – targeted health promotion and personalised management (at which stage the person would be referred for formal diagnosis) (Sharrock and Higginson 2008).

Training/education programmes

In this section we consider the education and training requirements for the Primary Care Liaison role. As this role is recommended to be a senior position, certain qualifications and experience of the potential post holder will be

expected. A number of 'extended' role training and education requirements were identified as important to the clinical and practice development of a Primary Care Liaison role, as well as rigorous and supported Continuing Professional Development (CPD) programme. How these would be used by a post holder would depend on prior qualifications and experience. There is a paucity of higher education provision that is specific to the field of dementia care, for professionals (who are non-mental health trained) working with people with dementia (Pulsford *et al*, 2007).

The Primary Care Liaison role is recommended to be taken up by a professional who already has extensive experience in the field and qualified to a standard that would have enabled synthesis of experience with theoretical and research knowledge and development. Therefore further development would need to be specific to the role.

Masters programmes

A *desirable* qualification would be a higher degree. There are a number of M level programmes in dementia care that could be accessed in the West Midlands (NHS West Midlands Clinical Care Pathways Project (Dementia) (In Progress), and there are also distance learning programmes available (Downs *et al*, 2009).

Our recommendation is that the programmes outlined below would be the most appropriate in developing the role:

- Advanced Assessment Skills – at M level – these are offered at a number of Universities in the West Midlands. This would enable the development of skills in physical assessment of people with long term conditions that are known to predict potential risk of dementia.
- Supplementary Prescribing – at M level is recommended as an 'extended' practice development depending on the professional background of a person undertaking the Primary Care Liaison role – these are offered at a number of Universities in the West Midlands

Furthermore the Association for Dementia Studies will have the following programmes in place in 2011. These modules will be part of the University of

Worcester curriculum and are designed to develop advanced practice in dementia care of practitioners who are already based in clinical settings.

- Specialist Practice in Dementia (mental health) Action Learning Set
- Early Intervention Service Action Learning Set
- Specialist Practice in Dementia (Leadership) Action Learning Set
- Specialist practice in dementia (person centred care)

Distance learning modules

Bradford University offer a range of university awards in dementia studies informed by an active program of research and knowledge transfer, including short courses and consultancy. These offer a broad dementia with potential to expand knowledge base in dementia care but may not be appropriate to the specific skills and extended role of the Primary Care Liaison role.

The programmes include: Certificate of Higher Education in Dementia Studies; Diploma of Higher Education in Dementia Studies; BSc (Hons) in Dementia Studies; MSc in Dementia Studies (incorporating specialized pathways in Training in Dementia Care and Dementia Care Mapping); Postgraduate Certificate in Change Management and Leadership in Dementia Care (Downs *et al*, 2009).

Continuing Professional Development (CPD)

We consider that CPD to be an essential component of the training and education for the Primary Care Liaison role. The following are recommendations are made in regard to CPD:

- Regular clinical placements (i.e. an initial two week placement and follow-up shorter placements at regular intervals) with Memory Services to maintain skills in screening and assessment
- Regular clinical placements with Community Matrons (who carry case-loads of patients with long term conditions). Also an initial two week placement and follow-up shorter placements at regular intervals.
- Attendance at any CPD programmes designed for GPs and related to dementia

Clinical supervision

Counselling skills are essential within the role and therefore it is recommended that one of the requirements of role development and support is that appropriate supervision is in place. This could be facilitated through critical companionship (Titchen and McGinley, 2003; Gribben and Cochrane 2006; Wright and Titchen 2003).

Recommendations

Three main areas of practice were identified for the Primary Care Liaison role in this consultation. These were: counselling; screening; and education and health promotion.

This report recommends the following

- There is a need for a Primary Care Liaison role to be developed within primary care teams
- The role should be at a senior level, as competencies identified require an experienced professional
- The role should be developed in partnership with Primary Care Teams
- Should must have strong collaborate links with Specialist Mental Health services, Primary Care District Nursing services and the third sector
- A useful team model would be that the role is placed within a 'GP cluster'
- Accessibility to GP records and collaborative working with GPs is essential within the role
- Personal continuing professional development (CPD) has a high profile in the role
- The role is supported by appropriate clinical supervision

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Appendix 2

Table: Competencies for Primary Care Dementia Liaison Role

COMPETENCIES	SKILLS
Knowledge/awareness of dementia and dementia related issues	Sound academic and up-to-date research and clinical knowledge of pathophysiology of dementia syndromes, i.e. types; stages; differential diagnosis issues including delirium; risk factors; co-morbidities; ageing and age related illnesses
	Knowledge of the relationship between depression and dementia for e.g. (depression predicts dementia) and concurrently (people with dementia get depressed, depression causes cognitive impairment))
	High level of awareness that the recognition of dementia is difficult in the early stages and that errors can have profound effects
	High level knowledge and understanding of policies; protocols; research evidence related to risks of developing dementia and of dementia care in following areas: primary care; acute care; third sector care, e.g. diagnostic processes and facilities; GP roles and responsibilities within statute; memory clinics and other diagnostic services
	High level awareness and understanding of the impact of a diagnosis of dementia (and/or terminal diagnosis) on the individual and their families and significant others
	High level awareness and understanding of the impact of physical, social, employment issues and emotional aspects of the environment on an individual at risk of/or with dementia
	Highly developed skills in liaison/negotiation within community dementia and other services/teams and across multiple agencies including service signposting across all health and social care provision. This may also include liaison / negotiating with employment services and benefits systems
	Comprehensive and sound knowledge of the Dementia Care Strategy
	Understanding of the West Midlands Darzi Pathway
	Ability to link with hard to reach clients i.e. multicultural/ethnic communities; younger people at risk of dementia through life style practices; minority groups such as LGBT (Lesbian Gay BI-sexual and Transgender); gypsies and travellers etc.
	Sound knowledge of risk factors (life style) associated with dementia, including knowledge of genetics and able to respond to questions about genetic risk
	Sound knowledge of medication used for management of dementia and risk factors related to other medication regimes
	Ability to conduct practice evaluations, audit and be involved at an advanced level in research projects
	Ability to identify the emotional and physical health needs of individuals who are at risk of/or have dementia

Comprehensive understanding of the behaviours of individuals with early cognitive impairment, dementia and other illnesses that have a neuropathology	Advanced awareness and understanding of the impact of potential losses associated with a diagnosis of dementia
	Understanding of barriers to diagnosis and reasons why people may not want to proceed to a formal diagnosis
	High level of knowledge and understanding of how behaviours impact on or reflect emotions or unmet needs
	Highly skilled in responding to the emotional, psychological and spiritual/existential experiences of individuals and their family members or significant others when facing a potential diagnosis of dementia. This will include skills in anger management and de-escalation techniques and anxiety management
	High level of awareness of the impact (on services capacity) through early diagnosis combined with sensitivity to individual wishes of people at risk
	Knowledge of Mental Capacity Act
Skilled in interacting with people with wide range of illnesses including mild cognitive impairment and dementia	Advanced communication skills in communicating with people with a wide range of illnesses including mild cognitive impairment, depression and dementia
	Advanced skills in breaking bad news and sound knowledge of approaches to this skill e.g. finding out what the patient already knows or suspects about their diagnosis; using the actual words "dementia" or "Alzheimer's disease" when talking to the patient (i.e., the use of explicit terminology); exploring what the diagnosis means to the patient.
	Ability to communicate (or prepare the individual to receive) significant news with sensitivity and support the individual during and following experience of having a diagnosis of dementia
	Highly developed skills in counselling an individual and their family members or significant others when facing a potential diagnosis of dementia
	Able to demonstrate an empathic approach when engaging/interacting with people who are distressed due to illness or loss
	Ability to show: compassion; empathy; care; patience; flexibility; open mindedness and a positive value base in relation to dignity, respect and honesty, choice, etc.
	Ability to respect, support and promote equality and diversity in how people respond to concerns/anxieties regarding a potential diagnosis of dementia, including respect for the right of the individual to choose not to know
	To be a skilled and assertive advocate in supporting individuals and their families and significant others through the screening/diagnostic processes
	Sensitivity to gender, cross cultural, and spiritual differences and issues
	Advanced communication skills in communicating with distressed individuals including the ability to communicate significant news with sensitivity

Skilled in interacting with families and or significant others of people at risk or with concerns about dementia	Sound knowledge of the significance of relationships when interacting with family members and significant other of people with dementia
	Highly skilled in balancing the needs of carers and those of individuals at risk of or with dementia
	Understand specifics regarding counselling and specialist requirements
	Ability to provide support and guidance to family carers where appropriate to assist them to understand the disease, its impact on the individual and some approaches to providing care
	Sensitivity to gender, cross cultural, and spiritual differences and issues
	To be a skilled and assertive advocate in supporting individuals and their families and significant others through the screening/diagnostic processes
	Understanding of the concerns of people related to the implications of receiving a diagnosis of dementia, particularly related to stigma and impact on independence
	Knowledge of adult vulnerability and abuse
	Ability to conduct a comprehensive risk assessment
Competent at providing education/facilitation and giving information to families and caregivers	Advanced skills and experience in presentation and teaching for a wide range of audiences (lay people/carers, school children to professionals)
	Confident in communication of information on a one-to-one basis about dementia, risk factors, services etc. to the individual at risk, family members and significant others and a range of professionals and lay persons
	Capacity to redirect and support/deliver interventions geared towards prevention and management of memory difficulties that are <u>not</u> dementia related
	Sound IT skills
	Knowledge of potential risk for dementia and skilled in health promotion and prevention strategies related to ‘at-risk groups’ e.g. alcohol and drug abuse; people with cardio-vascular disease; heart failure; diabetes etc .
	Knowledge of anxiety management techniques to reduce vascular stress
Skilled in conducting pre-diagnostic screening for people who have anxieties/concerns about dementia symptoms	Knowledgeable and skilled in the use of relevant pre-diagnostic tools for dementia screening
	Knowledgeable and skilled in ‘triage’ processes and ability to develop ‘triage’ tools specific to the area of pre-diagnosis screening for dementia
	Ability to be involved in the design and development of a screening tools for dementia
	Confidence in own abilities to carry out advanced clinical assess of people who are at risk of developing dementia
	Personal awareness of own limitations within the complexity of screening for dementia and mature ability to refer to appropriate services
	High level of awareness and understanding of impact of errors that may be made in diagnosis of early stage dementia
	Ability to conduct practice evaluations and audit in testing and validating screening instruments for pre-diagnosis of dementia

Personal qualities	Ability to work within teams at a strategic level including skilled at negotiation and integration with a complex range of healthcare professional
	Skilled in person-centred care approaches which encompass: valuing people with dementia and those who care for them; treating all people as individuals; looking at the world from the perspective of the person with dementia; recognising that all human life is grounded in relationships;
	Ability to practice maturely, ethically and in an anti-discriminatory manner
	Insight into own limitations and capacity to seek appropriate support to address limitations e.g. not presuming the ability to make a dementia diagnosis i.e. sub-typing
	Motivated and skilled in keeping up-to-date on all aspects of dementia research and practice
	Able to work independently
	Positive risk taker
	Confidence in own abilities and assertive
	Ability to work in a variety of settings
	Ability to think critically, reflectively and evaluate own performance and practice

Appendix 3

Job Description

Job Title: Primary Care Liaison Role (Dementia)

Grade: TBC

Location: TBC

Directorate: TBC

Accountable to: TBC

Report to: TBC

Key relationships: TBC

In order to meet the needs of the ORGANISATIONAL services you may be required from time to time to work outside your normal place of work Including carrying out assessments in the persons home. The ORGANISATION reserves the right to change your normal place of work to any other location within the ORGANISATION.

Job purpose and summary:

The post holder will provide needs led assessment in partnership with the multi-disciplinary team and facilitate screening and pre-diagnostic counselling support to people with concerns about or at risk of developing dementia.

The post holder will support/counsel the significant others of people with concerns about or at risk of developing dementia.

The post holder will provide counselling support to people identified as at risk (and their significant others) in decision making regarding proceeding to formal diagnostic services.

The post holder will use a triage system/approach to signpost clients to appropriate services i.e. to memory services for formal diagnosis or to appropriate care services if dementia is not indicated.

The post holder will be involved in the receipt and processing of referrals for pre-diagnostic screening for dementia. They will provide feedback to the multi-disciplinary team on the assessments, care, treatment and monitoring undertaken.

They will demonstrate good record keeping skills and will communicate effectively verbally and in writing with service users, professionals and carers.

In addition, the post holder will be involved in audit and service development for the pre-diagnosis services. They will offer advice and support to colleagues working in other service areas within the wider Community.

The post holder will foster and implement professional relationships and network across all community health services including the third sector and will maintain a multi-disciplinary team approach in all aspects of clinical and non-clinical performance.

The post holder will maintain the standards and requirements of professional and statutory regulatory bodies, adhere to relevant codes of conduct, understand the legal and ethical responsibilities of professional practice and maintain the principles and practice of client confidentiality.

The post holder will be proactive and take personal responsibility to ensure annual appraisal is maintained in line with organisational requirements

The focus of the work with service users will be pre-diagnosis counselling and therapeutic support. The post holder will need to develop and maintain 'best practice' within the service standards as outlined in Clinical Governance.

Responsibilities:

Take a clinical lead within the team and contribute to the further development of a pre-diagnostic and screening service for people with dementia and their significant others, and promote multi-disciplinary working, within the framework of relevant competencies.

Nature of work and job scale / PERFORMANCE INDICATORS

- 1 To liaise and work collaboratively with GP's in relation to all aspects of clients (and their significant others) care and progress.
- 2 Accept referrals and carry out screening using a triage approach.
- 3 Participate fully as a member of the multi-disciplinary team. In conjunction with the other team members participate in the formulation, review, implementation and monitoring policies for the service.
- 4 As a member of the team actively participate in identifying and monitoring the targets to ensure sound service delivery.
- 5 Build and maintain sound therapeutic relationships with clients and their families/carers and use a range of therapeutic skills.
- 6 Provide immediate support following diagnosis and disclosure and refer to appropriate services (i.e. Dementia Pathway Co-ordinator/ Dementia Advisory Service.).
- 7 Provide on-going support and counselling to individuals (and significant others) up to time of referral to appropriate services (i.e. particularly those regarding proceeding to formal diagnostic services).
- 8 Involve the client and his/her family and other carers in each stage of the systematic approach to assessment and screening.
- 9 As a member of the team develop 'best practice' to meet standards as outlined in national, local and other related guidance including clinical governance.
- 10 Ensure positive regard to all clients, regardless of illness, religion, culture and beliefs.
- 11 Record and report complaints actions, recommendations and monitoring process for improvements in accordance with the ORGANISATION Policy
- 12 To work as an independent practitioner and effectively manage own caseload.

Rider Clause

This is an outline of the post-holder's duties and responsibilities. It is not intended as an exhaustive list and may change from time to time in order to meet the changing needs of the Trust and Department.

Person specification

Job Title: Primary Care Liaison Role (Dementia)

Grade: TBC

FACTOR	ESSENTIAL	DESIRABLE
QUALIFICATIONS	<p>First Level Degree in an appropriate area of care relevant to dementia</p> <p>1st level registration with the appropriate professional body</p> <p>Qualification in counselling</p> <p>Evidence of ongoing professional development in dementia care and related areas of care</p>	<p>M level qualification in an appropriate area of care</p> <p>Qualified to prescribe medications</p>
EXPERIENCE	<p>Minimum 3 years post qualifying experience</p> <p>Minimum of 3 years in a senior role relevant to the post</p> <p>Evidence of working within memory services</p> <p>Experience of a variety of evidence-based therapeutic approaches for working with people with dementia</p> <p>Experience of healthcare and/or social care environments.</p> <p>Experience of case management and networking to support people with long term health and social care needs.</p> <p>Experience of working with older people with mental health needs and their carers/supporters and representatives in different settings including their own homes</p> <p>Experience of working with persons with a dementia and their supporters and caregivers</p>	<p>Previous experience of approaching and working with 'hard to reach' groups</p> <p>Experience in 'family therapy'</p> <p>Evidence of project management</p>
KNOWLEDGE, SKILLS AND APTITUDE	<p>Knowledge of a person-centred approach when supporting people</p> <p>Knowledge or experience of dementia care/support for</p>	<p>Advanced group or individual counselling skills</p>

	<p>people diagnosed with dementia and their caregivers</p> <p>IT competent i.e. familiarity with computers and some software packages</p> <p>Presentation and teaching skills</p> <p>Ability to write reports or articles</p> <p>Ability to employ a wide range of communication techniques</p> <p>Excellent verbal and written communications skills</p> <p>Awareness of communication challenges in mixed healthcare environments.</p> <p>Evidence of transferring academic learning and development into practice</p> <p>Commitment to personal development</p> <p>Willingness to progress academically and an ability and commitment to developing own practice</p>	
PERSONAL CHARACTERISTICS	<p>Empathy and understanding</p> <p>Responsible</p> <p>Desire to make a difference</p> <p>Caring nature yet objective</p> <p>Flexible</p> <p>Supportive</p> <p>Able to demonstrate personal coping skills through example</p> <p>Sense of humour</p>	
OTHER	<p>Prepared to undertake M level study if not already qualified to that level</p>	

Methods of assessment

Application form

Interview

Test (devise test) ? May be useful to include 1 to 2 hours with people with dementia as part of the interview or have someone on the interview panel to see how they interact

Presentation (at interview)

Examples of competency-based questions:

- Can you give us an example that shows your leadership skills?
- How would you deal with a difficult client?
- Can you give an example of a problem which you solved?
- What have been your major achievements and accomplishments?
- Can you give an example of working well as a team member?
- Can you give an example of your organisational skills?
- What are your long-term/future employment goals and objectives?
- How will you engage with 'hard to reach groups'?
- What are the challenges in taking forward this role?