

# Dementia skills and competencies for primary care liaison: a model for improving identification and timely diagnosis

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**Objectives:** The need to improve the response of primary care in terms of identification of people with undiagnosed dementia has long been recognised. The role of Primary Care Liaison was identified as a possible solution. An in-depth consultation was undertaken to identify professional competencies required in executing such a role.

**Methods:** Comprehensive literature and policy reviews were conducted to establish draft competencies or different options/combinations of competencies and competency levels. Consultations with a wide range of professional stakeholders ( $n=23$ ) and over 70 users and carers were conducted through focus groups, electronic document circulation and telephone interviews. An Equality Impact Assessment was conducted concurrent to the consultation.

**Results:** The literature demonstrated a clear need both to improve the rate of diagnosis for people with dementia and to improve the way in which the diagnosis is made. The stakeholder consultation repeatedly affirmed that without a diagnosis the person with dementia and their caregivers did not get access to the appropriate services, and validated the need for a role that would be able to improve a system that would deliver an early and 'timely' diagnosis. Competencies, based on the literature and policy documents, were developed and debated through the consultation processes. **Conclusions:** Three main areas of competency were identified: counselling; screening; and health education and promotion. The competencies identified require a skilled experienced professional approach. A useful team model would be that the role is placed within a 'GP cluster' as accessibility to GP records and collaborative working with GPs is essential within the role. Personal continuing professional development has a high profile in maintaining these competencies.

**Key words:** competencies; dementia diagnosis; primary care; workforce

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## Introduction

The number of people with dementia presenting to primary care services has grown significantly over the past 20 years and will continue to grow

for the foreseeable future. In the United Kingdom in 2007, the number of people living with dementia (but not necessarily diagnosed) was estimated to be 683 597 (Knapp *et al.*, 2007). A 2010 updated figure estimated the number to be around 820 000 (Alzheimer's Research Trust, 2010). This number is projected to reach 1 million by 2021 and rise to over 1.7 million by 2051 (Alzheimer's Society, 2012).

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Concern over delay in the diagnosis of dementia within primary care has been expressed for the past 40 years (Bamford *et al.*, 2004; 2007) and the lack of formal diagnosis, even for those who are experiencing significant cognitive loss, remains a problem for people living in the community (Brooker *et al.*, 2009). Several American and European studies have shown that 50% or more of people with dementia are not diagnosed (Valcour *et al.*, 2000; Löppönen *et al.*, 2003; Wilkins *et al.*, 2007; Perry *et al.*, 2008) and only one-third of people with dementia in the United Kingdom are ever formally diagnosed (National Audit Office (NAO), 2007; Waldemar *et al.*, 2007; Banerjee and Chan, 2008; House of Commons Committee, 2008). Diagnosis and contact, when made, often only occur late in the illness and in crisis when opportunities for harm prevention and therapeutic intervention are limited. The case has been strongly made for the benefits of early detection and intervention for people living with dementia and their families also in low- and middle-income countries (Prince *et al.*, 2011).

The pivotal role of the GP in the early identification, possible diagnosis/referral to Memory Services and subsequent management of dementia has long been recognised (Iliffe *et al.*, 2003; 2006; 2009; Woods *et al.*, 2003; Iliffe and Wilcock, 2005), and while diagnostic practice is improving the knowledge gained from research exploring the patient perspective is insufficiently absorbed into practice (Wilkinson and Milne, 2003). One-third of GPs express limited confidence in their diagnostic skills, while two-thirds lack confidence in management of behaviour and other problems in dementia (Turner *et al.*, 2004). Furthermore, information about management processes is not well evidenced in primary care records (Wilcock *et al.*, 2009). Health professionals who fail to investigate patients presenting with dementia symptoms can delay diagnosis, denying patients and caregivers early intervention, which could improve quality of life for both the patient and the caregiver (Cahill *et al.*, 2008).

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 among 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 (NAO, 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 (NAO, 2007; Prince *et al.*, 2011).

Comprehensive guidelines for the diagnosis and management of dementia have been developed by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE), with recommendations that a diagnosis of dementia and dementia subtypes 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 to 2007, GPs in England 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 NAO (2007) survey found that 67% of GPs said they had a register and 79% reported that it prompted them to review cases, although types of review varied widely. In all, 70% of GPs said that a lack of time during surgery visits prevented them from doing as much as they would like for people with dementia.

However, patient records are currently not accessible to other professionals outside the GP practice, making coordination of care difficult (NAO, 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 core issue for practitioners was resources, that is, the availability of personnel and time to respond to patients and their significant others who have concerns or anxieties regarding the possibility of having dementia. Service 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, taking into account their approach to coping and their capacity to adjust to change (Milne and Peet, 2008).

The concept 'Primary Care Liaison Worker' (PCLW) originated from the West Midlands

'Darzi Dementia Care Pathway' (Saad *et al.*, 2008), a report from the West Midlands Darzi Dementia Clinical Pathway Group that detailed the challenges and issues for service provision faced by increasing longevity and the changing demographic profile in the Region. The need to find ways of improving diagnosis is echoed in many National Dementia Strategies (eg Department of Health (DH, 2009a). It was proposed that the PCLW would enable those with suspected dementia to access an assessment process directly and with expediency. 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, possibly undertaking pre-assessment counselling. They could also act as a point of access for those requiring information and coordination across service boundaries.

The aim of this project was to establish a set of competencies associated with such a role in primary care, using literature and consultation with key stakeholders and families and people living with dementia. This consultation was conducted on this role as a collaborative activity between the University of Worcester and Staffordshire University. It brought together two parallel but complementary streams of work: development of the role of (1) a PCLW 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. Both consultations were undertaken concurrently using the same stakeholder and service user groups.

## Method

### Literature review

For the purposes of this study, an 'integrative review' (Khoo *et al.*, 2011) was undertaken, which included policy documents, job descriptions, opinion pieces and guidelines, as well as research studies. This enabled a review in which the reviewer's voice is dominant and focused on ideas and results with a complex structure of topics and sub-topics. In this way, the literature is consulted in depth rather than simply reviewed for evidence. The key search terms were combinations of the following: *dementia*; *Alzheimers*; *cognitive*

*impairment*; *liaison*; *community*; *primary care*; *stigma*; *awareness raising*; *screening*; *diagnosis*; *support*; *recruitment*; *education*; *skills*; *competencies*. Inclusion criteria were English language materials since 2000 (although some seminal papers were used). UK literature was the preference but relevant non-UK literature was considered. Databases searched included: Pubmed; Age-info; Social Care online; National Library for Health; PsychINFO; Cumulative Index to Nursing & Allied Health (CINAHL); OVID Nursing Collection; Google Scholar.

The main searches were conducted using the terms dementia OR Alzheimers OR cognitive impairment. These terms also activated retrieval of mild cognitive impairment articles. When the above terms were combined with screening AND diagnosis AND primary care AND community, there were over 800 hits, of which more than 200 articles were examined closely. These terms were also combined with stigma, with more than 500 hits of which more than 200 articles were examined. This also activated retrieval of some of the articles used in an Equality Impact Assessment (EIA) Report. Numerous further searches were conducted plus a wide range of 'grey literature' was examined. This included policy documents, relevant job descriptions and education programmes in combinations related to different aspects of the competencies, for example: education in primary care; higher education; triage; practice nurses; health visitors. The number of hits for these was not recorded. The search took place over January–March 2010. The review was used to establish draft competencies or different options/combinations of competencies and competency levels. The literature was further examined in the preparation of this paper.

An EIA was conducted concurrent to the consultation using DH Guidance (DH, 2008). It was based on the structure of the EIA for the National Dementia Strategy (DH, 2009b). The EIA was used to consider the possible impact of the two new roles in dementia care in the West Midlands on people according to their age, disability, ethnicity, religion and beliefs, gender and sexual orientation, and took account of the literature and feedback from stakeholders, including users and carers. It was used to identify any potential issues for any of those groups and ensure that the introduction and operation of the

new roles took account of potential issues to reduce potential inequality. The EIA identified that there is very little literature on the impact of dementia on the above groups and that these roles could usefully improve diagnosis in all sections of the community.

## Consultation

### *Consultations with professional stakeholders*

- i) Stakeholder meetings of known dementia and primary care leads across the West Midlands region.
- ii) Widespread circulation of documents as the project proceeded to allow for stakeholders to respond electronically.
- iii) Telephone conversations and meetings with interested parties.

Relevant stakeholders were identified (including organisations that could offer feedback/links and representation of service users and carers). In all, 14 stakeholders were consulted using focus groups and another nine were consulted electronically. They were representative of a wide spectrum of the community services within the West Midlands, reflecting a wide range of 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 practice managers. Before full consultation, a questionnaire was used to identify the perceived:

- need for such a role
- gaps in the service
- level of skills and knowledge required (from basic level to autonomous advanced practitioner) of a person conducting pre-diagnostic assessment for dementia.

Responses to the questionnaire were collated and laid the foundations for draft competencies that were circulated to stakeholders. Focus group discussions were audio-recorded and transcript material was examined using the draft competencies as a framework.

It was noteworthy that there was confusion among stakeholders regarding the difference between the Primary Care Liaison role and that of the Dementia Pathway Coordinator role, and

how the transition of patients from the PCLW to the Dementia Pathway coordinator would be managed by the teams. Stakeholders questioned whether there was a need for two new roles rather than only one. They were also concerned that the general public could become confused about the two different roles. This concern was verified based on responses from users and caregivers.

### *Consultations with people with dementia and their supporters*

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 during consultation for the EIA. In all, over 70 service users and carers were consulted. Service users found it more difficult to discuss the pre-diagnosis situation, but easily identified with and discussed service needs following diagnosis.

The approach used to address this challenge was to collect 'stories' about experiences between 'suspicion' of cognitive impairment and actual diagnosis. As this was not a research study, these cannot be reported in detail. Twenty-one 'stories' were recorded in which participants reported that the period between noticing early symptoms and getting a diagnosis ranged from 2 to 10 years. Three people with early dementia shared their personal experiences, nine 'stories' were told by caregivers in the presence of the person with dementia and nine were collected through internet sites (not an exhaustive search).

## Competencies development

Draft competencies were developed on the basis of stakeholder feedback (including professional stakeholder feedback from the questionnaire), and the literature and policy documents (including existing job descriptions for similar roles and (then) 'work-in-progress' by the Stafford University Team (Tsaroucha *et al.*, 2011)). The iteration process involved the following steps:

- 1) distribution of drafts to stakeholders
- 2) audio-recorded focus group discussion with stakeholders; and/or electronic responses to drafts from stakeholders

- 3) redrafting of competencies
- 4) electronic consultation with stakeholders
- 5) redraft of competencies
- 6) electronic consultation with small 'expert' group of stakeholders for validation and
- 7) final competency documents.

Draft competencies documents included comment column for responses until the final document.

## Results

### 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. 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 what a dementia pathway should 'look' like; where in the pathway particular professionals should/could be positioned; and concerns about the range of dementia 'roles' that were being established throughout the United Kingdom and the risk of confusing the general public about these roles. At times, the responses were overwhelmingly about funding, that is, 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 among stakeholders that priority should be given to '*up-skilling*' existing primary care staff across all professions.

Service users repeatedly reported on issues and experiences on how their diagnosis was managed by the primary care services, reporting, in the main, negative experiences, although there were also some very positive experiences, particularly when care was managed by a supportive GP. Service users reported that they become confused about services while 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 stakeholder groups supported the key recommendations made by Milne and Peet (2008) and guidelines developed by NICE-SCIE (2007). Therefore, the development of the 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. In addition, 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 Whitehurst, 2001). Consequently, all following competencies are identified as being in keeping with a high-level professional.

### Recommended competencies of the PCLW

The following competencies were identified as essential for a person undertaking this role.

### Recommended competencies to improve dementia diagnosis

A description of the competencies over which there was support in the literature and broad consensus from stakeholders is shown in Table 1.

An area where there was considerable debate is whether pre-diagnostic screening for people who have anxieties/concerns about dementia-like symptoms should be conducted within primary care. 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. From the 70 service users and families in our focus groups, the average time from suspicion of the possibility of dementia to diagnosis was between four and five years, a situation that is upheld within the literature (Valcour *et al.*, 2000; Löppönen *et al.*, 2003;

**Table 1** Competencies identified to improve dementia diagnosis in primary care

<i>Knowledge/awareness of dementia and dementia-related issues</i>	Up-to-date clinical knowledge of the pathophysiology of dementia syndromes and the relationships between dementia and other pathologies, as well as a high level of knowledge of services.
<i>Comprehensive understanding of the behaviours of individuals with MCI, dementia and other illness that have a neuropathology</i>	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 was particularly pertinent around patients with possible MCI.
<i>Skilled in interacting with people with a wide range of illnesses including MCI and dementia</i>	This required sensitivity and high-level skills to engage in discussions about assessment, information giving and possibly referral for diagnosis of dementia, particularly if pre-diagnostic screening for dementia was carried out. 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 <i>et al.</i> , 2006; 2008). Competencies were identified around counselling skills, advanced communication skills and being 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 (ie the use of explicit terminology); exploring what a possible diagnosis means to the patient. The 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.
<i>Skilled in interacting with families and or significant others of people at risk or with concerns about dementia</i>	This competency is closely related to competencies above. Understanding the importance of relationships was seen as essential by users and they focused on the importance of families and relationships with much more emphasis than did the professional stakeholders. Competencies include a sound knowledge of the significance of relationships when interacting with family members as relationships are central in the care-giving process (Henderson and Forbat, 2002; Forbat, 2003; Askham <i>et al.</i> , 2007). Relationships can provide insights into care exchanges and embedded in this approach is that the accounts of the person with dementia is taken seriously (Forbat, 2003; Wilkinson and Milne, 2003; Bamford <i>et al.</i> , 2004).
<i>Competent at providing education/facilitation and giving information to families and caregivers</i>	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, 2009a; 2009b) 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, for example general public, caregivers, schoolchildren, professionals, etc.
<i>Skilled in person-centred care approaches</i>	Professionals and users 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.

MCI = mild cognitive impairment.

NAO, 2007; Waldemar *et al.*, 2007; Wilkins *et al.*, 2007; Perry *et al.*, 2008). 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

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issue of routinely screening older people for cognitive impairment is controversial. 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; 2006). Stakeholders supported finding or developing the 'ideal' instrument that would be accessible to, and easily used by, both doctors and nurses (Iliffe and Manthorpe, 2004).

This competency, as identified by Saad *et al.* (2008), proposes introducing a triage process. Consequently, this competency requires 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 in the literature that were specifically designed for the pre-diagnostic assessment for dementia. Mental health triage systems developed in Australia (Broadbent *et al.*, 2007; Sands, 2007) and Canada (Cristine *et al.*, 2007) offer possible models that could be used for this role. In the Sands (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.

### Considerations on how the primary care liaison role should work

A 'liaison' role, by definition, is a person who initiates and maintains communication between different groups or units of an organization. Where the person in such a role would be positioned was a matter of some debate among stakeholders. Community Matrons felt that the

GP surgery was 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).

Stakeholders had indicated a number of professionals who would be capable of performing the role of a PCLW. 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.

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; Trickey *et al.*, 2000; Koch and Iliffe, 2009); however, health visitors are now completely focused on children and young person services. Practice Nurses, who regularly encounter the general population of older people (Manthorpe *et al.*, 2003), may be well placed to fulfil this role and there are also a number of Primary Care Trusts in England who employ 'Nurse Advisors for Older People' (Worcestershire NHS UK, 2011) or Nurse Consultants for older people (British Geriatrics Society, 2011).

### Discussion

Routine screening of older populations is controversial and the efficacy of such screening is unsubstantiated (Fletcher *et al.*, 2004). Ideally, a highly selective, focused and sensitive case finding process should be used in screening for dementia in primary care (Stuck *et al.*, 2002; Iliffe and Orrell, 2006), and there is evidence that a structured initial assessment by a specialist nurse is an accurate method of determining a diagnosis of cognitive impairment, when compared with formal multidisciplinary team judgement (Page *et al.*, 2008). 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 role should be at a senior level, as competencies identified require a skilled experienced professional approach. The role should be developed in partnership with Primary Care Teams but should have strong collaborative links with Specialist Mental Health services, Primary Care District Nursing services and alongside private and charitable care providers. A useful team model would be that the role is placed within a 'GP cluster' as accessibility to GP records and collaborative working with GPs is essential within the role.

### Implications for practice

Rather than seeing the new role in addition to the already skilled professionals that work within primary care, it may be that the competencies should be viewed as being developed across the team. This would involve up-skilling and professional development around a dementia-specific knowledge base, whereas some of the skills around counselling and education are transferrable across different age groups. In order to operationalise this, there needs to be an education and development programme within primary care so that the challenge of increasing numbers of people with dementia requiring timely diagnosis can be met.

### Limitations and future research

The consultations only took place in one region in England. The West Midlands has within it very urban and very rural communities and a wide mix of socio-demographic groups. Given this, it is likely that the consultation process would yield similar results within other English regions. Research is now needed on how to operationalise these competencies in practice and whether such a role or competencies within a GP cluster actually makes a significant difference to outcomes for people and their families who are currently undiagnosed with dementia.

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