Establishing a community of practice for dementia champions (innovative practice)

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Abstract
This discussion paper considers the currently evolving roles of dementia champions and describes an initiative designed to support their activities. The aim of this initiative was to establish a county-wide group that has a shared group identity and sufficient critical mass that is able to identify and implement dementia training and development needs for the health and social care workforce. The approach used to achieve this aim was a Dementia Champion Community of Practice Project, which involved dementia leads in various NHS Trusts. Whilst this approach might be effective at practitioner level, the Dementia Champion Community of Practice Project experience suggests that if such initiatives are to be sustainable they need to be strategically placed within networks that can bring together service providers, educators and commissioners.

Keywords
Community of Practice, dementia alliance, dementia champions

Introduction and background
Dementia champions (DCs) are seen as playing a key role in the transfer and dissemination of knowledge within and across agencies and organisations involved in caring for people living with dementia (Banks et al., 2013; Mayne, Allan, Reynish, MacLullich, & Cunningham Vardy, 2014). Different health care providers have implemented the DC role
in various ways. Some define all health care professionals as DCs, whereas others identify key clinicians or create salaried posts designated to lead on dementia-linked initiatives within the organisation. In order to support the process of establishing and implementing a variety of DC roles across organisations and professions, Health Education England commissioned a project that would ‘develop and maintain a system wide initiative to support DCs across Hertfordshire’. The project was conceptualised as developing a ‘Virtual Dementia Champion Community of Practice’ (CoP) through which Dementia Champions’ inter-professional and inter-disciplinary sharing and transfer of knowledge could be facilitated. In theory, CoPs are useful multi-professional and multi-disciplinary fora for healthcare professionals to engage in. They are seen as providing the means for shared staff and organisational learning and development that transcend hierarchies, disciplinary and organisational divides (Aveling, Martin, Armstrong, Banerjee, & Dixon-Woods, 2012). Communities of Practice commonly function strategically within and across existing networks (Conklin, Lusk, Harris, & Stolee, 2013; Kislov, Harvey, & Walshe, 2011; Thomson, Schneider, & Wright, 2013), as virtual CoPs that practitioners join (Ikioda, Kendall, Brooks, De Liddo, & Buckingham-Shum, 2013), or as practice learning environments, where identification around shared learning takes place (Dupuis, McAiney, Fortune, Ploeg, & de Witt, 2014; Grealish, Bail, & Ranse, 2010; Soubhi et al., 2010). More recent forms of CoPs in the UK are networks such as Dementia Partnerships (2014) (http://dementiapartnerships.com), and the Dementia Action Alliance (2014), which is an umbrella organization that might be described as a fusion of virtual CoPs and a practice-oriented network of organisations involved in dementia care (http://www.dementiaaction.org.uk).

The roles of DCs are context dependent and tasks vary. Despite the policy imperative, most DC roles have developed organically rather than strategically. It is the context in which a CoP is located that determines the mechanisms that need to be employed to support its functioning (Ho et al., 2010; Ranmuthugala et al., 2011; Scottish Dementia Champions Managed Knowledge Network (MKN), 2014). Little is known about how the context of the DC role shapes how dementia champions engage with their peer group and with opportunities for shared learning, encouragement and professional development.

Against this background, the paper now considers the experience of setting up a Dementia Champion Community of Practice (DEMCoP) in Hertfordshire with specific reference to the organisations involved in this process, and the extent to which it is currently able to influence and develop services to address the needs of people with dementia.

**Aims of the DEMCoP Project**

The broad aim of the Dementia Champions Project (DEMCoP) at the University of Hertfordshire was ‘...to establish a county wide group that has a shared group identity and critical mass that is able to identify and address dementia training and development needs for the health and social care workforce’. The DEMCoP Project built on a history of shared working between health and social care in the commissioning and planning of dementia services. It set out to:

- to create a shared focus, and identify a framework through which priorities for dissemination of information, ongoing dementia training, coaching and development needs could be identified;
to provide an interactive platform that identifies priorities and supports training and development in dementia care across clinical settings;

- to create an infrastructure that can support the achievement of the dementia strategy linked implementation targets (including Commissioning for Quality and Innovation (CQUIN)) across Hertfordshire NHS and local authority providers.

**Methods**

A two-pronged approach of first identifying interested individuals and organisations, and then providing access to an online information resource was used. As particular foci and areas of interest emerged, for example by clinical setting or dementia care issue, the DEMCoP project sought to create infrastructures of specialist support and shared learning. Project activities began by hosting an inaugural Dementia Champions Symposium in partnership with the NHS in Hertfordshire and the Alzheimer’s Society. Subsequent meetings were held with representatives from different NHS primary, secondary and mental health provider units. A dedicated DC online-site was provided on the University of Hertfordshire server, which required DCs to register as a member. Online access was covered by project funding. This is supplemented by a bi-monthly newsletter that was initially sent to known DCs and is now sent to various interest groups. The format ensures that there is news about county initiatives and events in dementia care, update on recent dementia research or policy initiatives, interviews with a DC, or discussion points and updates on dementia training and resources. Face-to-face activities by the researcher working on the DEMCoP project involve meetings with local DC groups (hospital and community based) to map dementia activity, encourage and sustain relationship building, and develop new initiatives to raise awareness and involvement of health and social care staff. Project links established with different DC groups and organisations have laid down communication strands. The approach adopted by the project sought to be bottom up and context sensitive.

**Findings**

The findings presented in Table 1 comprise the various activities undertaken, together with facilitators and barriers that were highlighted during project implementation. The DEMCoP project is ongoing, and its role of supporting the development of groups of DCs will continue to evolve.

**Discussion**

In its current stage of development, the Hertfordshire DEMCoP Project has some of the aspirations and attributes of a Community of Practice, but does not readily conform to any of the types of models described in literature. Its bottom up approach positions it closely to a practice model, but the project also networks with NHS Trusts, DCs and educators, and seeks to become part of a wider regional alliance. Unlike in other studies of CoPs, where participants were either a member of a professional group or organisation, DCs and professionals in this study are only linked by tenuous job specifications, are based in multiple organisations, and hold this role along with other
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| Hosted an inaugural Dementia Symposium in partnership with the NHS in Hertfordshire and the Alzheimer’s Society, which was attended by 120 health-care professionals from across the county. | **Facilitators:** Participation was free and supported by service managers  
The event was attended by 120 people  
**Barriers:** Only a handful of attendees had DC as a recognised title although many saw this as an important part of the role. There was no common understanding of DC roles or how to implement them, or of what effectiveness would look like. |
| Online resource that brings together best evidence and web links to other resources, organised by topic and featuring videos of DCs talking about recent innovations.  
Videos of DCs talking about recent innovations.  
Creation of option for discussion groups. | **Facilitators:** Use existing tested facilities that provide access to UH resources.  
**Barriers:** UH system designed for undergraduate and postgraduate students and not for practitioners who may have intermittent contact as members of a Dementia Knowledge Network.  
DCs resistant to registering as a member of the online DC community.  
Limited opportunities for interaction and feedback when participants log on. |
| Identified clinical leads in the Hertfordshire Partnership NHS Foundation Trust (HPFT), the West Hertfordshire Hospitals NHS Trust, the East and North Hertfordshire NHS Trust, and the Hertfordshire Community NHS Trust. | **Facilitators:** The involvement of county dementia leads and links to their pre-existing networks enabled rapid engagement, an overview of what was currently available across the county, who led it, and which groups of people with dementia were served.  
**Barriers:** Key individuals who led dementia initiatives in health and social care changed jobs due to organisational changes. This affected continuity and underlines the importance of a linked infrastructure to provide an ongoing focus and point of contact to accommodate the challenges of change. |
| Attend regular meetings once a month with DCs in their NHS Trusts. Tentative job descriptions for DC’s roles were developed. | **Facilitators:** NHS Trusts with dedicated posts and staff in place for dementia care are able to disseminate information and lead innovation (albeit CQUIN informed) in their organisation.  
**Barriers:** Risk creating a clique; this would reduce the reach of the network to organisations and people who are not working in or with the two main NHS Trusts. |
| Bi-monthly newsletters to approximately 180 individuals identified as either having a DC role or a stated interest in dementia and/or dementia care. The newsletters feature a range of items and provide links to recent research articles. | **Facilitators:** Tangible output that promoted dissemination of news, recent research findings and upcoming events. Medium for people to join DEMCoP, contribute, share their achievements and submit short articles and items.  
**Barriers:** Reliant on key people to contribute material. A transient workforce, which makes it difficult to keep tracking people. |

(continued)
responsibilities. This meant that the main route and linkage mechanism of DEMCoP project activities concentrated on learning from individuals at the practitioner level, and on sharing how they understood the role and remit of DCs in response to policy driven, deadline specific activities such as CQUIN targets which aim to identify people with dementia using the service. DCs are presently not being canvassed to influence education or training curricula, so the DEMCoP Project surveyed DCs within NHS Trusts, which resulted in the delivery of tailored study days for various groups. The study days had the dual aim of being an educational resource and creating action-learning groups to continue virtual and face-to-face learning together. The introduction of the specific DC study day, together with the increased uptake of already existing dementia awareness study days, prompted the development of specific dementia modules in the post-qualifying curriculum.

Most DCs’ current roles in acute Trusts are governed by shifts and rotas and leave little if any time to access computers and read, post, blog, or download and engage with new information. This meant that DCs did not engage with the virtual CoP set up by the university. The aspiration that a virtual group would bring together a diverse and scattered workforce has, so far, not been realised. For an emergent CoP that is grounded in the learning of its members, which defines and redefines methods of working together, it might be more meaningful for the online linkage to come later, rather than to be set up at the

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<td>Survey of DCs’ priorities for dementia related education and training (last quarter of 2013). Found an ongoing need for dementia training on broad issues around dementia care, and for education for staff with little experience of working with people with dementia. Held subsequent study days at the University of Hertfordshire led by a Senior Lecturer with expertise in dementia. Discussions on how to best link the aims of DEMCoP with those of the CLAHRC, EAHSN (Eastern Academic Health Science Network) and the Dementia Alliance. Steering Committee: involved key stakeholders from the NHS Trusts and LA and the educators to review progress and provide links to other county-wide initiatives.</td>
<td><strong>Facilitators</strong>: Interdisciplinary work between Practice Development/education and Research at UH DCs perceive sharing experiences and good practice as helpful. <strong>Barriers</strong>: Competing priorities make it difficult to get staff off their rotas to attend training sessions. Staff frequently lack opportunities to access online fora at their workplaces.</td>
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<td><strong>Facilitators</strong>: Funded networks designed to link best evidence and practice with dementia as an explicit focus. <strong>Barriers</strong>: Risk of duplication of activity. <strong>Facilitators</strong>: Health care professionals provide insights into practice related issues which can lend direction to the development of DEMCoP on behalf of the DCs. <strong>Barriers</strong>: Maintaining participation over time and refreshing the membership of the group.</td>
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*aCQUIN = Commissioning for Quality and Innovation. People with dementia are often not diagnosed and, due to communication difficulties, stay in hospital much longer than necessary. In order to avoid prolonged and expensive stays the UK Department of Health (DOH) offers financial incentives to hospitals to implement admission and discharge policies (UK Government Department of Health (DOH)), 2012.*
beginning of the project. For a bottom up approach to work and ensure that theory and practice remain connected (Kislov et al., 2011) there is a need for health care, social care and educator providers to see DCs as a valuable resource when planning dementia care and service development. It might therefore be best for the fledgling Dementia Champion CoP to become part of a network that can lend the infrastructure required to not only raise the profile of the DC role, but also to influence and develop services. Expressed differently, the CoP needs to become a network within a network, and lateral links need to be joined to, and supported by, vertical links (Aveling et al., 2012). A CoP needs robust and multi-pronged support during its first few years, until it reaches a critical mass that is resilient enough to cope with key changes in composition of membership and/or changing policy agendas (Conklin et al., 2013; Dupuis et al., 2014; Thomson et al., 2013).

In a progressively diverse healthcare economy consideration needs to be given to how Dementia Champion CoPs can provide the links between entities or groups who can cooperate county-wide. The aims of the Hertfordshire DEMCoP Project increasingly coincide with, and complement the aims of, regional groups and national initiatives such as the Academic Health Science Networks (AHSNs) and the second wave of CLAHRCs, the majority of which have a focus on dementia, on the needs of the oldest old, and on key targets set out in the UK Dementia Strategy (DoH, 2009). Their emphasis on implementation of best evidence into practice, and the involvement of a range of provider organisations and research centres, provides an organisational framework within which the CoP can fit.

**Conclusion**

Health care related CoPs are increasingly located within larger networks, where they act as separate entities with a clear remit concerning their contributions toward the aims and objectives of health care policy. The role and contribution of a DEMCoP to an organisation’s ongoing commitment to the improvement of services for people with dementia has great potential. Capacities need to be sustained and feed into a wider infrastructure that has dementia as a strategic and service priority and can develop and grow the role of DCs. Some of the anticipated patient benefits set out by the National Dementia Strategy (DoH, 2009) and the CQUIN framework (DoH, 2012) are contingent upon the direction and leadership of DCs in putting into place systems and procedures that encourage enhanced communication and interaction with people living with dementia and with their caregivers, and their overall involvement in helping to create person-centered care pathways from admission to discharge and continuity of care in the community. The wide variation of how DCs’ roles and responsibilities are defined, and the development of such roles in organisations that are themselves subject to frequent change and reorganisation requires the continuity and stability of a framework to create a forum in which members can interact if the goals of the CoP as an entity are to be achieved and sustained.

**Recommendations**

This discussion paper suggests that if CoPs that foster dementia awareness and dementia sensitive care in the health and social care workforce are to be successful and sustainable, they need to be supported by an organisational framework that offers resources that can maintain relationships and create opportunities for pooled learning.
Conflict of interest

None declared.

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References


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