

The role, remit and training needs of Dementia Champions:

Results from an on-line survey

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DISCLAIMER:

This report presents findings of a study commissioned by Health Education East of England. The views expressed in this report are those of the authors and not necessarily those of Health Education East of England and/or of any of the professionals contacted.

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Copy of paper published in phase 1 of the DEMCoP project

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1 INTRODUCTION AND BACKGROUND

Dementia Champions play a critical role in implementing the goals of the National Dementia Strategy [1, 2]. Whilst there is no common definition of what a Dementia Champion is, their role is often to act as change agents in improving the experience, care, treatment and outcomes for people with dementia, their families and carers. This can be in general hospitals, community and long term care settings and at the interface between hospital and community services. Professionals and clinicians across Health and Social Care have taken up the role of Dementia Champion in addition to their existing responsibilities. The Dementia Champion Community of Practice (DEMCoP) project was designed to create a shared focus for the role of Dementia Champions, to identify priorities for education and training, to disseminate information and to link activities with existing and emerging dementia alliance networks. Connections were established with local stakeholders such as NHS Trusts, Local Authorities, representatives in the Social Care sector and regional Dementia Alliances [3]. The first part of the DEMCoP Project was completed in 2014 [4]. In its second phase the DEMCoP Project focused on exploring how Dementia Champions (DCs) perceived their role, its remit, and which training they thought they would need in order to meet the needs of people living with dementia and to co-ordinate their care in various clinical contexts. The findings are presented in this report.

1.1 Aims and objectives

The specific aims and objectives of this part of the project were to establish:

- ❖ The professional roles held by dementia champions and whether or not the DC role was formally recognised
- ❖ What the DC role entailed and if dementia champion specific responsibilities were reflected in job specifications
- ❖ The various clinical contexts that DCs worked in

- ❖ DCs' perception of the adequacy and applicability of dementia education and training

2 METHODS

Data were collected via an on-line survey (Bristol Online Surveys) which was developed, piloted and launched in January 2015. The survey web-link was emailed to Dementia Champions (DCs) who were already on the DEMCoP data base held by the University of Hertfordshire. This data base included the names and contact details of people who were identified by their organisations as DCs, and a smaller self-selected group who had submitted a request to join DEMCoP. Responses were anonymous although some of the information provided could possibly have identified their workplace. The survey consisted of 25 questions which were a mix of multiple choice, multiple answer, and text questions. The survey took 10 minutes to complete. It remained open for one month and weekly reminders were sent to potential respondents to encourage participation.

3 FINDINGS

Of the 224 emails sent to Dementia Champions (DCs) 36 (16%) were returned as delivery failures. Of the 188 potential respondents 35 participated in the survey, one of whom was not a DC and was excluded. This left 34 valid responses, which constitutes a response rate of 18%. Whilst this was disappointing, the value of the survey remains in profiling the role and clinical context of DCs' work and to learn more about how to support practice through dementia education and training for this scattered group of professionals.

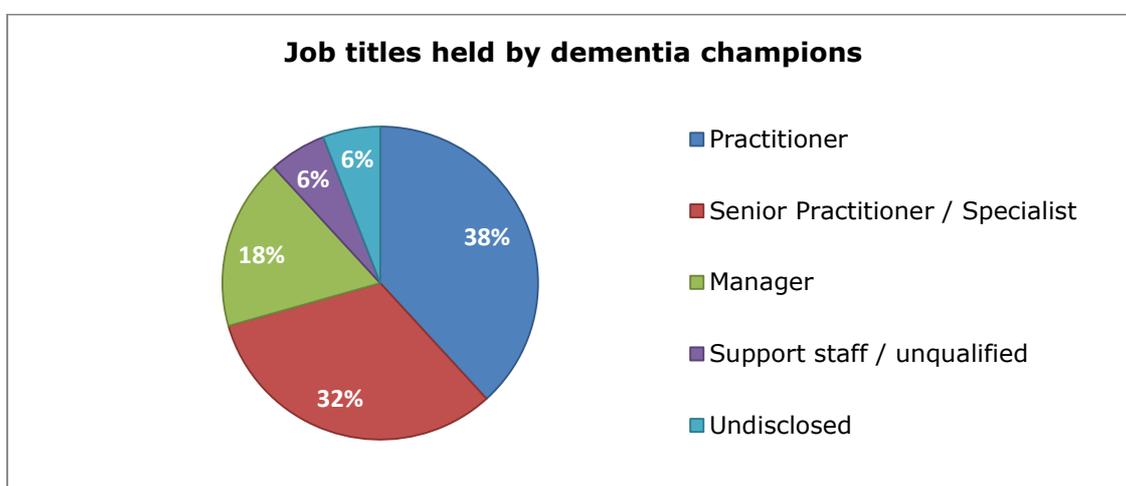
3.1 Sample characteristics

As shown in Table 1, 20 (59%) were aged between 51 and 60 years. Nearly all (32, 94%) were female.

Table 1: Age distribution of respondents

Age	N (%)
21-30	1 (3)
31-40	5 (15)
41-50	7 (21)
51-60	20 (59)
61+	1 (3)
Total	34 (100)

Of 34 respondents 13 (38%) were practitioners (nurses, therapists and emergency staff), 11 (32%) senior practitioners, six (18%) held managerial posts, and two (6%) were support staff. Two respondents (6%) did not disclose their role as this would have identified them. This is shown in Figure 1.

**Figure 1: Job titles held by dementia champions**

As indicated in Table 2, the majority of respondents worked in hospital settings. One response was undisclosed.

Table 2: Clinical areas of work of DCs

Clinical area	NHS Trust N (%)	Social Care N (%)	Total N (%)
Acute	14 (52)	0	14 (43)
Community	5 (18)	2 (33)	7 (21)
Mental Health	1 (4)	0	1 (3)
Primary Care	1 (4)	0	1 (3)
Social care / day services	0	4 (67)	4 (12)
Outpatients	5 (18)	0	5 (15)
Theatre	1 (4)	0	1 (3)
Total	27 (100)	6 (100)	33 (100)

This sample is characterised by a mature age group of staff who work predominantly in NHS Trusts and hold patient facing roles across clinical settings.

3.2 Was the DC role formally recognised?

As shown in Table 3, in 21 (62%) cases the role of Dementia Champion was formally recognised. However, only six of the 21 DCs had received a job-specification that outlined additional duties and expectations of a DC. Of the 13 (38%) respondents whose DC role had not been formally recognised one had received a job-specification. This might seem like a contradiction, especially since when asked how they had become a DC, they said *"I was asked and happily agreed"* [RES31]. However, the respondent also stated that *"...responsibilities were added, but I do not carry the title of DC"* [RES31]. It appears that the 'title' has not been conferred. Six of the seven respondents who had received a job-specification worked in NHS Trusts.

Table 3: Formal recognition of DC role reflected in job description

		Given a job-spec for this role		N (%)
		Yes	No	
DC role formally recognised	Yes	6	15	21 (62)
	No	1	12	13 (38)
Total		7	27	34 (100)

3.3 Acquisition of DC role and colleagues' awareness of role

It had been assumed that the majority of DCs volunteer for the role. However, in this sample there was an even split between those who had self-selected and those who had been identified for the role. Of the 34 respondents, 15 (44%) had put themselves forward for the role of Dementia Champion, and 15 (44%) agreed to step into the role when asked. The remaining four were either asked and felt they could not say no, or considered themselves a DC anyway, although they were not formally asked to step into this role and did not carry the title. Participants were

asked whether or not colleagues were aware of their DC role, and if so, how. As shown in Table 4, around one third of respondents (12) stated that 'the team are aware', eight thought that others only knew because they wore a badge or their name was on a board/poster as the 'go-to' person, and four thought that their colleagues were entirely unaware of their DC role and responsibilities. Only three respondents held a lead role in dementia.

Table 4: Colleagues' awareness of respondents' DC role

	N (%)
Other's don't know	4 (12)
Badge/board/poster	8 (24)
Team are aware	12 (35)
Job role, active involvement, training	7 (20)
Dementia lead	3 (9)
Total	34 (100)

3.4 Dementia Champions' specific responsibilities

The multiple answer question concerning DCs' responsibilities indicated that 25 (74%) of the 34 respondents disseminated dementia related information to immediate colleagues, 13 (38%) advised staff on how to support people with dementia (PWD), eight (24%) were a 'named expert', and seven (21%) were responsible for staff training, as shown in Figure 2. Other activities and duties included supporting clinicians to identify people with a possible undiagnosed dementia, helping them to signpost patients, caring for dementia patients during their short stay, and attending meetings. Some did not have any specified responsibilities.

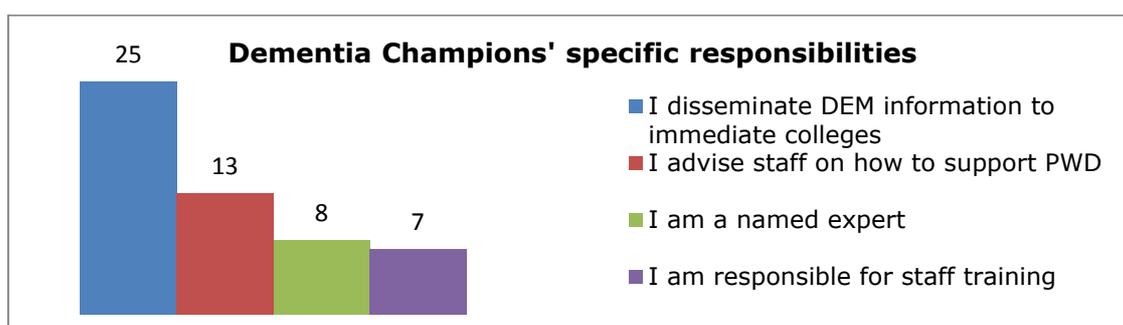


Figure 2: Dementia Champions' specific responsibilities

As highlighted in Table 5, most of the DC responsibilities were carried by Practitioners and Senior Practitioners. Clinical roles were highly specialised and included specialist nursing in endoscopy, theatre, diabetes and renal, as well as emergency medical technicians.

Table 5: DC responsibilities by job title/job role

	Named expert	Advise staff	Staff training	Disseminate information	Other
Manager	3	2	1	6	1
Senior Practitioner/Specialist	1	5	3	8	1
Practitioner	4	5	2	8	3
Support staff/unqualified	0	0	0	2	1
Undisclosed	0	1	1	1	1
Total	8	13	7	25	7

Staff encounters with people with dementia (PWD) varied. As shown in Figure 3, only six (18%) of respondents had intensive encounters with PWD.

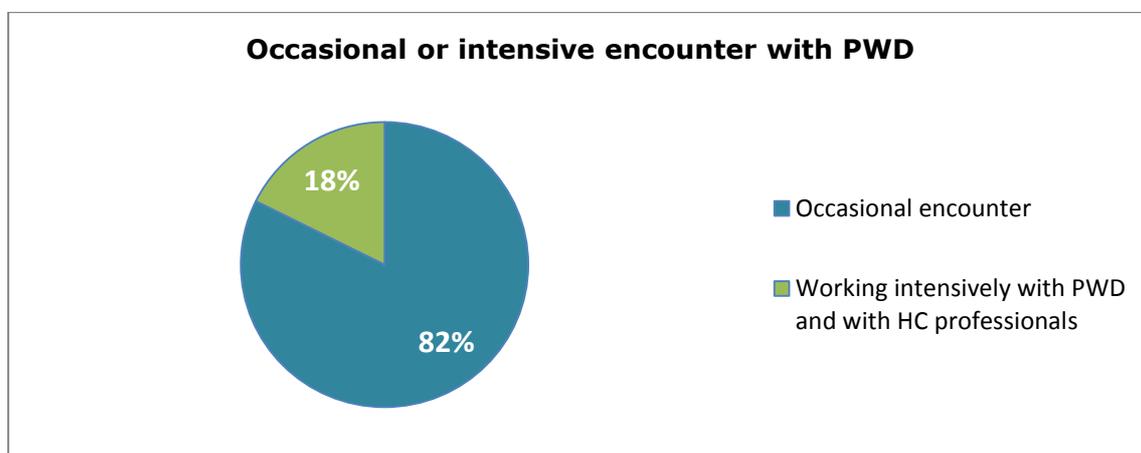


Figure 3: Encounter with PWD: occasional or intensive

The six individuals who worked intensively with people with dementia and with health care professionals who specialise in dementia care were registered nurses and community based staff as indicated in Table 6.

Table 6: Respondents having intensive contact with PWD and health care professionals

Clinical area	Staff role	Job title
Day services	Manager	Assistant Manager
Social Care	Manager	Team Manager
Community	Practitioner	Occupational Therapist
Acute	Senior Practitioner / Specialist	CNS
Acute	Senior Practitioner / Specialist	Matron
Acute	Senior Practitioner / Specialist	Senior Sister

3.5 Dementia specific education and training

Dementia specific education and training received in the last two years in addition to education/training for their post varied from half-a-day's input to courses taken that were linked to a dementia qualification such as an award, certificate or a diploma. As indicated in Table 7, most respondents had received a full day's training. Others had participated in a four-day foundation programme and/or accessed on-line modules. Some participants had a mix of different inputs. Three respondents carrying the title of DC had not received any training, although they held specialist professional roles in Acute Trusts.

Table 7: Dementia specific education and training received*

	N (%)
1/2day training	9 (26)
Full day training	18 (53)
Short course without accreditation / qualification	4 (12)
Course linked to dementia qualification (award/certificate/diploma)	3 (9)
No training received	3 (9)
Other	5 (15)

* Based on 34 replies. Percentages do not sum to 100 as multiple options could be selected.

3.5.1 Perceived adequacy of training

Table 8 shows that 20 (59%) of respondents thought that the dementia education and training received were adequate for the job they did, but 14 (41%) stated that it did not address dementia related challenges encountered in daily practice.

Table 8: Respondents' perceived adequacy of training

Perceived adequacy of training	N (%)
Yes	20 (59)
No	14 (41)
Total	34 (100)

Participants who stated that the training received was adequate in relation to their job role identified the most applicable and beneficial aspects of training had been skills training to reduce stress in people with dementia and their carer, safeguarding, and interventions in dementia care. This is shown in Table 9.

Table 9: Most important aspects of training*

	N (%)
Skills to reduce stress in PWD and their carers	15 (44)
Safeguarding	15 (44)
Interventions in dementia care in my work	13 (38)
Difference between delirium, depression and dementia	11 (32)
Knowing what happens in the brain	11 (32)
Applying the Mental Health Capacity Act	9 (26)

* Based on 34 replies. Percentages do not sum to 100 as multiple options could be selected.

Additional 'other' responses included being able to advise and signpost families (n=1), a better knowledge of referral processes (n=1), the coordination of community based care (n=1), and knowledge about interventions in dementia care in my work environment (acute trust) (n=1).

The 14 respondents who thought that training had been inadequate included managers, senior practitioners and practitioners. Perceived training adequacy was not significantly associated with position, job title, or length of time in current job. However, as shown in Table 10, there was a statistically significant association between perceived training adequacy and the organisations that DCs worked for (p=0.036, Fisher's exact test). In Trust A, only five (36%) DCs thought that training had been adequate, in Trust B four (67%) DCs, whilst in Trust C five (83%) DCs thought that their training had had been sufficient.

Table 10: Perceived training adequacy by organisation

		Organisation							Total
		NHS Trust A	NHS Trust B	NHS Trust C	NHS Trust D	Social Care A	Social Care B	Un-disclosed	
Training adequate	Yes	5	4	5	1	5	0	0	20
	No	9	2	1	0	0	1	1	14
Total		14	6	6	1	5	1	1	34

There was also a statistically significant association between perceived training adequacy and the clinical areas DC's worked in ($p=0.019$, Fisher's exact test). Whilst most respondents working in the community and in Social Care thought that training had been adequate, the majority of respondents (71%) working in acute care thought it had been inadequate. This is shown in Table 11.

Table 11: Perceived training adequacy by clinical area

		Clinical area of work							Total
		Acute	Community	Mental Health	Primary Care	Social care/ day services	Out-patient	Theatre	
Training adequate	Yes	4	6	1	1	3	5	0	20
	No	10	2	0	0	1	0	1	14
Total		14	8	1	1	4	5	1	34

Of the 14 respondents who perceived training as inadequate, 10 (71%) felt the need for 'more specialised training', which referred to practical aspects of learning and training, and more knowledge on 'specialist' topics pertaining to their particular job role, and recognised qualifications in dementia care.

3.5.2 The need for additional training

Of 34 respondents, 14 (41%) had felt that training was inadequate (see Table 10 and Table 11), but when dementia champions were asked whether or not they thought they needed more dementia specific training 26 (76%) answered 'yes'. The

text answers that were provided referred to wanting more updates and more information in relation to specific topics such as end-of-life care and what happens in the brain in dementia, diagnosing dementia and how to manage behaviours that are challenging. Ten respondents who thought that training had been inadequate wanted to attend a course that has a recognised qualification (Table 12). There was no consensus about the preferred method of delivery for training.

Table 12: Delivery of training that would work best for me*

	N (%)
A course that has a recognised qualification	10 (29)
Training with other practitioners involved in dementia	9 (26)
Group based teaching in the workplace	8 (24)
Workshops that are informal updates	7 (21)
Blended learning	6 (18)
Teaching away from workplace	5 (15)
Online with self-assessment	5 (15)

* Based on 34 replies. Percentages do not sum to 100 as multiple options could be selected.

Respondents were asked if they had to target one particular group in their workplace as in need of further dementia education and training, which one they would identify. As indicated in Table 13, clinical support staff and registered nursing were the most often cited groups, followed by medical doctors and management. Four respondents suggested that everyone should be targeted.

Table 13: Suggestions of groups of staff to be targeted for further training*

	N (%)
Clinical support staff	21 (62)
Registered nurses	21 (62)
Medical doctors	13 (38)
Management	11 (32)
Qualified ambulance staff	7 (21)
Other: everyone	4 (12)

* Based on 34 replies. Percentages do not sum to 100 as multiple options could be selected.

When asked what would help them to achieve more for people with dementia, 14 (41%) replied 'more knowledge and training'. Few provided any detail about what

this should focus on and an eclectic list of issues were identified. Respondents' replies are shown in Table 14.

Table 14: Achieve more for PWD – what would help? *

	N (%)
More knowledge and training	14 (41)
Recognising dementia	4 (12)
More time and staff resources	3 (9)
Knowing the needs of the patient	2 (6)
Services of dementia patients at the hospital	2 (6)
Working with patients in their home	1 (3)
Specialist input – joint visits with MH team	1 (3)
Personalised care packages	1 (3)
Integrated Health and Social Care	1 (3)
Early diagnosis	1 (3)
Other / missing	4 (12)

* Based on 34 replies. Percentages do not sum to 100 as multiple options could be selected.

3.6 Is the term *Dementia Champion* appropriate?

Of 32 respondents, less than half (44%) thought that the term 'Dementia Champion' reflected their dementia responsibilities appropriately. As shown in Table 15, 18 (56%) respondents thought that the term was overused, did not reflect the responsibilities of their role, did not like this term, or did not use it.

Table 15: Is the term *Dementia Champion* appropriate for your role?

	N (%)
Yes	14 (44)
No	18 (56)
Total	32 (100)

As one respondent remarked, "I have noticed that people smile when they hear the word 'champion' in relation to dementia. To be honest, I would like a definition of the term" [RES10]. Another respondent stated "...I just say that I am dementia trained, I never say 'champion' [RES19].

A thoughtful observation came from one respondent in the community about the implications of giving titles that are not tied to qualifications to practitioners: "...[the word] *champion is being used to allow staff to develop skills without any formal recognition of the extra knowledge, ability, responsibility that goes with that. This is true not just with dementia but with a range of champion functions (we use safe-guarding, MCA [Mental Capacity Act], pressure ulcer, to name a few). Whilst this is a great career development I do worry that it represents a move towards more and more complex functions being undertaken by increasingly low staff grades*" [RES30].

DISCUSSION

Survey respondents were predominantly female and held professional roles as practitioners, senior practitioners and managers. Their clinical environments included Acute Trusts, a Community Trust, a Mental Health Trust, and community settings. There was no consensus about the level of preparation that a DC should have, and there was some ambivalence about the dementia champion title. Only seven had a job-specification, and how the role was enacted varied. The majority had received a day's dementia training, which reflects the 'tier 1' training [5] designed to increase awareness of dementia and the dissemination of dementia specific information. This raises questions about the level of expertise the organisation they worked for thought was necessary to fulfil a DC role. Staff had found basic training helpful, but recognised its limitations.

The identification of personnel across health and social care who take responsibility for promoting the support of people with dementia and their carers in their workplace signals an organisation's commitment to improving care. However, survey findings suggest a lack of clarity about the scope of the role and the skills and knowledge Dementia Champions needed to fulfil it. Whilst there is a policy consensus about the importance of developing a framework for education and

training in dementia that develops clinician expertise [6], for some of those in DC roles it seemed to have been less clear where they fitted in. A recent report on how the workforce has been prepared to care for people with dementia highlighted that very few programmes offered progression and accreditation [3]. Findings evidenced a tension between being seen as someone interested in promoting the care of people with dementia, being the 'go to' person for information and signposting, and being an expert. The level of preparation respondents had received could not equip them to provide specialist input though some participants could see the value of having a validated expertise in dementia care that could be linked to professional development.

Champions are change agents. It is clear that enthusiasts can be influential in achieving behavioural change in their peers and workplace through challenging practice and, as most of the respondents did, through the dissemination of information. To achieve a significant behavioural change however, champions may need to work within a network of support that can make their role explicit and exploit inter-professional and cross organisational working [7].

LIMITATIONS

The low response rate and consequently small sample size constitutes a limitation. Low participation might reflect the fact that individuals holding the role of Dementia Champion did not necessarily see themselves as 'champions' and so did not think the survey was for them. Not all participants used the title. Respondents came from various clinical settings and the associated challenges described are similar to those in other parts in the country. Overall, the survey results contribute to and confirm a growing body of literature [3-6, 8, 9] on the expectations surrounding the role of DC, of the practicalities of carrying out this role in daily practice, and of the need for developing structures that can accredit dementia education and training.

CONCLUSION AND RECOMMENDATIONS

The aims of the survey were to establish (i) the professional roles held by Dementia Champions and whether or not the role was formally recognised, (ii) what the DC role entailed and if dementia specific responsibilities were reflected in job descriptions, (iii) the various clinical contexts that DCs worked in, and (iv) DC's perception of the adequacy and applicability of dementia education and training. Respondents' professional roles included nurses, therapists and emergency staff at practitioner, senior practitioner and managerial level and some clinical support staff. The majority of respondents worked in hospital settings. Most DCs did not have intensive contact with PWD or with health care professionals who specialise in dementia care. Whilst the DC role was recognised in more than half of the cases, only one fifth of respondents had received a job-specification for the DC role. Responsibilities for Dementia Champions included disseminating dementia specific information, advising staff on how to support people living with dementia, caring for patients, helping to signpost patients and being responsible for staff training. The majority of staff working in acute care stated that dementia specific education and training had been inadequate. Survey results suggest that the deeper learning required by staff could be provided through the requirement of accredited training to ensure that the DC role can be fulfilled appropriately and in accordance with the demands of clinical settings. It would be interesting to explore further how different clinical settings pose different challenges for dementia care. There could be value in aligning role-specification with education and training that is competency based and formally recognised.

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