



Anglia Ruskin
University

Cambridge Chelmsford Peterborough

Dementia Buddies Evaluation

Research report

Dr Claire Preston
Professor Stephen Moore
April 2015

Corresponding author:

Claire Preston
Research Fellow
Health and Wellbeing Academy
Anglia Ruskin University
Eastings 204
East Road
Cambridge CB1 1PT
claire.preston@anglia.ac.uk

Funding for this project came from the Health and Wellbeing Academy, Anglia Ruskin University and South Essex Partnership University NHS Foundation Trust

Executive Summary

This report covers a year-long evaluation of a dementia buddies scheme that has been piloted in two mental health trust units in an Essex hospital. The scheme recruits volunteers to visit and befriend patients on the wards. It was set up with the primary aim of supporting carers/relatives and enabling increases in the one-to-one non-clinical attention patients receive, so these aspects were the focus of the evaluation. However, as our research illustrates, carer or patient experience cannot be divorced from the setting in which they occur. We find it is useful to think of wards (or units) as microcosms, with various, interrelated factors contributing to the experience of all those involved. If an intervention is introduced into such a setting, it both affects and is affected by that setting. As a result, the evaluation also enabled analysis of the scheme's wider interaction with the functioning of the wards and its resultant impacts on staff and volunteer buddies, as well as patients and carers.

Overall, we found a high level of support for the scheme, with many staff, carers and buddies detailing the positive impacts they feel it brings both to themselves and to the patients. We also heard a number of criticisms of the scheme and although such views form a minority of those expressed, they were particularly useful in identifying various factors which are key to determining the scheme's performance. We have termed these 'enablers' but they also serve as a list of recommendations to consider when designing and implementing a buddies scheme in a hospital unit or ward. They are as follows:

1. Organise the scheme in such a way as to maximise the individual capacity of patients to respond during a buddy visit, in particular to avoid them being asleep or adversely medicated.
2. Make sure all staff are 'on-board' in regard to the benefits of person-centred care for all patients. Person-centred care should be uniformly respected and practiced in the setting.
3. Ensure that the scheme complements current provision rather than competes with it. Paid staff should feel that this is the case. The way in which the scheme is introduced is important in this regard.

4. Training of buddies should explain and justify what might otherwise appear to be cumbersome requirements of NHS systems. Similarly, where possible, systems should be tailored to accommodate volunteer support. Training should also prepare buddies for the realities of engaging with people who have dementia.
5. Enable relatives to meet the person running the scheme, meet the buddies themselves, and see the buddies 'in action' with patients.

These enablers contribute to what, in the best-case scenario, is a virtuous circle of impacts from the Buddies scheme, as illustrated in Figure 1 (page 5) and summarised in Table 1 (page 43). In this best-case, relatives trust the buddies and feel that the person they care for is benefitting from the scheme. As a result they are able to step back a bit, allowing the buddies to relieve some of their strain. Staff, in turn, are heartened by seeing these positive impacts and also by seeing patients get more of the one-to-one, friendly attention staff feel they need. The buddies feel valued and useful as a result.

Where the enablers are weakly represented or absent, the scheme can be undermined and a more destructive circle of impacts ensue. Low levels of trust and respect and a poor fit between the functioning of the scheme and ward are key characteristics of this more negative circle of effects: staff demonstrate poor levels of trust and respect for the scheme, seeing the buddies either as competing with their role or as ineffectual; relatives appear not to trust staff entirely and therefore see buddies more in terms of a watchful eye; this in turn feeds back into the lack of staff support for the scheme; the buddies feel ill at ease on the ward and/or that their input is not needed; as a result they find buddying unrewarding; patients miss out on the potential benefits of buddy visits.

Our research showed that the scheme performed better, according to these criteria, on one unit than on the other unit. We have renamed these units 'Spring' and 'Summer' for the purposes of this report. Spring unit tended more towards the best-case scenario. Some of the differences between the units may be attributable to the fact that patients tend to stay longer on Spring and that this facilitates deeper relationships between patients and staff, between staff and relatives/carers and also between patients and buddies. However, our research also indicates the presence of other factors on Spring which are conducive to the

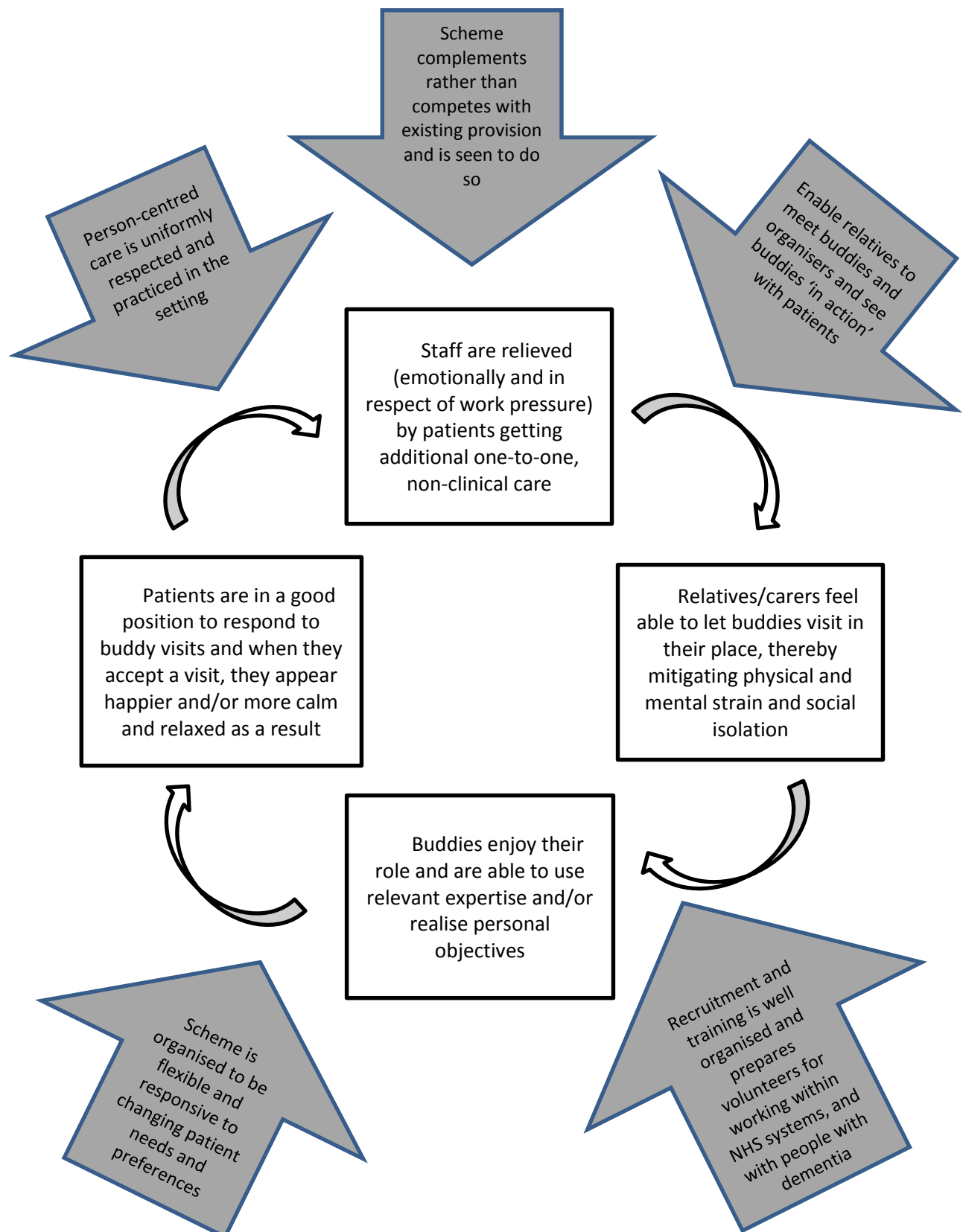
scheme's success, such as high levels of trust and respect between staff and buddies and universal 'buy-in' among staff about the benefits of person-centred care for 'their' patients.

In addition, although we identified trust between relatives and buddies as a key enabler of the scheme, on neither ward did we find evidence that this was lacking to any destructive degree. This is thanks to the scheme being organised in such a way that it's easy and reassuring for relatives to meet the person who runs the scheme, to meet the buddies themselves, and to see them 'at work'.

The evaluation is useful not only for identifying recommendations for enacting a dementia buddies scheme in specialist wards. It has wider implications for volunteering in hospital settings more generally and, in this respect, our findings corroborate and build on those of other recent research. The challenges healthcare provision currently faces make the prospect that volunteering can provide a partial 'solution' all the more attractive. However, in order to realise the potential benefits of volunteering, attention should be paid to the stress points which occur when integrating volunteers into hospital settings. At an individual level, these include the possible tensions between paid employees and volunteers – as other studies have found. What our research adds is the observation that this phenomenon can play out at a wider level too. Where volunteers are part of a scheme, tensions can arise if there is any incompatibility between the culture of the scheme and that of the setting where it is introduced. Culture in this context is not, however, static and in the best-case scenario, the cultures of a volunteer scheme and ward can feed off each other and develop in a manner which is positive and productive for all those involved.

Figure 1: Best-case scenario, in which enabling factors contribute to a virtuous circle of positive impacts for the Dementia Buddies scheme

Key: arrows = enabling factors; boxes = positive impacts



Contents

Executive Summary	2
Acknowledgements	8
List of tables, figures and boxes	8
1. Introduction.....	9
2. Context of the Research	9
2.1 The Dementia Buddies Scheme	10
2.1.1 Recruitment, training and support of volunteer buddies	11
2.1.2 Recruitment of relatives/carers and patients to the scheme	11
2.2 Immediate Context: The Units Hosting the Dementia Buddies Scheme	12
2.3 Wider Context: Dementia, Volunteering and Informal Care in the UK and Essex	12
2.3.1 The prevalence and costs of dementia	12
2.3.2 Policy overview.....	14
2.3.3 The role of volunteering and informal care	14
3. The Evaluation	17
3.1 Evaluation Approach	17
3.2 Background Research and Literature Reviews	19
3.3 Interviews and Survey	19
3.3.1 Interview participant recruitment.....	20
3.3.2 Interview process and rationale.....	21
3.3.3 Analysis.....	21
4. Findings from the Survey and Interviews.....	21
4.1 Impact on Relatives/Carers of People with Dementia	22
4.1.1 “Me time” - holidays, chores, hobbies and health.....	23
4.1.2 Avoiding social isolation	23
4.1.3 Lessening the emotional strain	24
4.1.4 Letting go and relieving guilt	25
4.1.5 A trusted person to “keep an eye”	26
4.1.6 From carer to volunteer	27
4.2 Impact on Patients	27
4.2.1 Circumstantial benefits – one-to-one, non-clinical friendly attention.....	29
4.2.2 Observed benefits - verbal and non-verbal expressions of enjoyment and calm.....	31
4.2.3 Reasons for not benefiting – from individual to ward-level circumstances.....	32
4.3 Impact on Clinical and Support Staff	34
4.3.1 Satisfaction at seeing patients get one-to-one, non-clinical, friendly attention.....	34
4.3.2 A reminder and supplement for person-centred care and compassion	35
4.3.3 More relaxed, calmer patients	36

4.3.4 Tensions between buddies and paid staff.....	36
4.4 Impact on Buddies	38
4.4.1 Turning personal experience into expertise.....	38
4.4.2 Therapeutic and emotional rewards	39
4.4.3 Some challenges of dementia buddying	39
5. Conclusion	40
6. References	44
Appendix - Dementia care interventions: a review of literature	48

Acknowledgements

We would like to thank the Dementia Buddies scheme leader and all those who participated in discussions and interviews for their invaluable help in this evaluation.

List of tables, figures and boxes

Tables, figures and boxes	Page
Figure 1: Best-case scenario in which enabling factors contribute to a virtuous circle	5
Box 1: Dementia: an introduction	13
Box 2: Theory-driven evaluation in healthcare settings	18
Table 1: Summary of the Dementia Buddies positive impacts and undermining factors	43

1. Introduction

The South Essex Partnership University NHS Foundation Trust (SEPT) commissioned Anglia Ruskin University to carry out an evaluation of a dementia buddies scheme which has been piloted on two inpatient units SEPT manages at a hospital in Essex. This report details the results of that evaluation, which ran from March 2014 to March 2015.

This evaluation considers whether the scheme delivers its primary objectives: supporting the carers/relatives of individuals with dementia in the units concerned; and providing those individuals more one-to-one non clinical attention. We also consider the processes behind those objectives and identify factors which enable or hinder their realisation.

The first part of the report briefly describes how the Dementia Buddies scheme was set up and functions in the units where it has been piloted (sections 2.1 and 2.2). Section 2.3 describes the wider context of the scheme, both within Essex and nationally. Section 3 explains our approach to the evaluation and how we carried it out. It also covers the review of comparable interventions which we conducted as an initial stage of the research and which is summarised in the Appendix. Section 4 presents the findings of our analysis. This is organised according to the impact of the scheme on those involved: the carers/relatives (4.1), the patients (4.2), the clinical and support staff (4.3) and the buddies (4.4). Each of these sections is preceded by a summary list of the impacts. Section 5 provides a conclusion to the whole report.

To protect the anonymity of our research participants, we have changed the names of the units where the scheme was piloted and anonymised all direct quotes. For the same reason, we have also arbitrarily assigned genders to people, which may or may not reflect their actual gender.

2. Context of the Research

This section describes the origins and organisation of the Dementia Buddies scheme and the context in which it was piloted. It also covers the wider context of dementia and volunteering in the UK and Essex.

2.1 The Dementia Buddies Scheme

The Mickey Payne Memorial Foundation was set up to honour the memory of Mickey Payne, who had dementia and passed away in August 2010. The Foundation was created to support relatives and carers of people with dementia. In June 2013, SEPT (South Essex Partnership University NHS Foundation Trust) joined forces with the Foundation to launch a pilot for the Dementia Buddies scheme in a unit SEPT manages in a hospital in Essex. This unit provides specialist mental health services for older people. The first buddies started visiting patients on the ward in August 2013. Two months later, the scheme was introduced onto a second, adjoining unit with a similar, but not identical, remit.

Dementia Buddies are volunteers who befriend people with dementia, taking a person-centred approach. They are allocated to specific patients, with the aim of building a strong and supportive friendship. The model is that patients on the buddy scheme have two or three visits a week at a time agreed with their relatives/carers. However, if an individual makes it clear they do not want a visit from a buddy when they arrive, the scheme advises that the buddy should leave. Likewise, if a buddy arrives and the patient is unreceptive because for example they are asleep, the buddy curtails their visit. Where a patient is receptive to being visited by a buddy, during that time the buddy will engage in whatever activity or pastime seems to best suit the patient. For example, they may just sit and hold the person's hand and perhaps talk to them, without expecting much verbal response in return. Alternatively, they might have a two-way conversation or engage in some sort of activity, such as doing a jigsaw, or looking through photos or pictures which seem of interest or relevance. On occasions buddies have built models with patients, painted their nails, made Christmas cards and read to patients. Such activities are facilitated by a set of materials which the person who runs the scheme has put together and which are kept on one of the wards. When buddies visit an individual, they are asked to record the details of their buddying session in a book (the date/time and what took place during the session). This stands as a record and also a resource for other buddies and for relatives/carers to access if they want to. The book is one way in which buddies can find out about an individual before they visit him or her for the first time. They can also read the 'This is me' forms, which the ward completes on patients as a matter of course (see section 2.1.2). In addition, the scheme leader will communicate with buddies before they visit to share

information learned in conversation with carers/relatives when they join the scheme. All of this enables a person-centred approach on the part of the buddies.

2.1.1 Recruitment, training and support of volunteer buddies

With SEPT's support, the scheme recruited 21 volunteers, 3 men and 18 women, between June 2013 and February 2015. Volunteers have stayed with the scheme for an average of 6-7 months. They undergo normal steps in the process of volunteer recruitment to SEPT, including DBS and occupational health checks. Additionally they must take part in extra training as a dementia buddy. There have been three sessions of buddies training since the pilot of the scheme began in June 2013. Training for the first cohort of buddies took place in July 2013 and was delivered by a dementia specialist from SEPT and the Buddies scheme leader. The second cohort training took place in March 2014 and was delivered by a dementia-specialist volunteer from SEPT, and again by the scheme leader. The scheme leader delivered training for the third cohort on her own. The latest training approach requires new buddies to shadow the scheme leader for two or three sessions of her buddying on the wards. The scheme leader organises the buddies rota (although for a while this was done by another volunteer) and makes herself available to buddies should they want to discuss any difficulties or challenges they face. She is also the main contact point for relatives/carers who want to discuss the timing or content of buddy visits.

2.1.2 Recruitment of relatives/carers and patients to the scheme

The model for recruiting people to the scheme begins by clinical staff talking to relatives/carers who express an interest in the scheme. The ward manager then makes a referral and SEPT passes the details of that patient's relatives/carers on to the scheme leader. She gets in touch with the relatives/carers to discuss the scheme in more detail and clarify whether they are happy to take up the referral. She underlines at this point that there is no charge for the service. If relatives/carers do agree to go ahead, the scheme leader then has a conversation to fix a suitable time for buddy visits and to find out more about the likes/dislikes and background of the person to be visited. This helps the buddies respond in a way tailored to that individual. The first buddying session is carried out by the scheme leader, who then selects a suitable buddy to continue the visits. She is also a regular buddy to several people herself.

2.2 Immediate Context: The Units Hosting the Dementia Buddies Scheme

The Buddies Scheme has been piloted on two inpatient units at hospital in Essex, which are managed by SEPT. Summer Unit is a 24-bedded, mixed sex, assessment unit for older people with mental health illness that affects memory and other functions associated with old age. Spring Unit is a 24-bedded, mixed sex, challenging behaviour dementia unit. Before Spring 2014, it had been a continuing care unit for older people with specialist mental health needs related to a diagnosis of dementia but it has been undergoing a gradual transformation to a challenging behaviour dementia unit since that time.

The wards give formal support to carers, including carers' support packs, regular newsletters and carers' drop-in surgeries. The wards encourage a person-centred care ethic by, for example, gathering information on the personal histories of patients through 'This is me' forms, which ask about the person's life, family, work and interests. Occupational therapist and/or activities co-ordinators have worked on both wards at various times with the remit of providing stimulating activities to enhance care.

2.3 Wider Context: Dementia, Volunteering and Informal Care in the UK and Essex

This section describes the wider context of the Dementia Buddies scheme, covering the prevalence and costs of dementia nationally and within Essex, the policy background, and the role of volunteering and informal care in meeting the challenge of dementia.

2.3.1 The prevalence and costs of dementia

Dementia is a widespread and challenging public health issue, estimated to have an overall economic impact in the UK of just over £26 billion a year, equivalent to about £32,250 per person¹. An estimated 850,000 people in the UK have dementia and forecasts suggest this number could reach 1 million by 2025². These predictions are made by combining figures on prevalence levels with forecasts of population ageing in the UK (since the risk of dementia rises notably with age).

¹ Alzheimer's Society, 2014

² *ibid*

In Essex, these national trends are reflected locally, but the situation is more acute because the proportion of over 65s is higher than the national average and is expected to reach around 20% of the population by 2021³. This means that the estimated figure of over 22,000 people currently living with dementia in the geographical area of Essex, Southend and Thurrock is expected to increase to 35,000 by 2025⁴.

Recent research provides some optimism regarding some forecasts, however⁵. It indicates that the prevalence of dementia fell between 1989 and 2008. So, projections that fail to take more recent prevalence figures into account may be overstatements⁶. This is potentially good news but, nonetheless, the present challenge remains acute, particularly in regard to the strain on healthcare systems.

Dementia accounts for £4.3 billion in healthcare costs in the UK per year⁷.

In hospital settings, it creates

particular challenges: dementia is associated with longer lengths of stay, delayed discharges, readmissions and inter-ward transfers⁸. Around 40% of people aged over 65 in hospital have dementia, resulting in an estimated excess cost in the average general hospital of £6 million

Dementia: an introduction

Dementia is an umbrella term describing a set of symptoms that occurs when various diseases or conditions affect the brain. It consists of the general breakdown of intellect and personality, with loss of memory, attention and emotional control. It is a complex condition in which environmental, psychological, emotional and biological factors can all affect an individual's wellbeing.

The different types of dementia depend on the underlying illness or condition which causes it. Alzheimer's disease causes about 50-70% of dementia cases. It typically results in a dementia characterised by confusion and impaired thought and speech. Vascular Dementia is the next most common type of dementia and is caused by deterioration of blood vessels in the brain, often associated with mini strokes. Other types include Dementia with Lewy bodies and Fronto-temporal Dementia.

About 10% of people with dementia have more than one type at the same time. Current thinking suggests this 'mixed dementia' is more prevalent at very old ages.

³ Essex Insight, 2013; ONS, 2014

⁴ Essex County Council and partners, 2012

⁵ Mathews et al, 2013

⁶ Note that the national projections cited above (from Alzheimer's Society, 2014) do take recent prevalence data into account.

⁷ Alzheimer's Society, 2014

⁸ Department of Health (DoH) 2013, Alzheimer's Society, 2009

a year⁹. The pressures brought by high numbers of hospital patients with dementia are catalogued in various recent reports¹⁰.

2.3.2 Policy overview

The policy response to dementia has been building since the Department of Health announced in 2007 that it would be a national priority. In 2009, the Department published a National Dementia Strategy¹¹ and made its implementation a priority in 2010. The strategy identifies 17 objectives, specifying improvements in three key areas: raising awareness and understanding; early diagnosis and support; and living well with dementia. In 2012, the focus on dementia was further underscored by the publication of the Prime Minister's Challenge on Dementia¹².

In Essex, these policy developments were reflected in the publication in 2012 of the Essex, Southend and Thurrock Dementia Strategy, which provided an overarching statement of how those involved would work together to meet the objectives of the National Strategy, while allowing the flexibility to respond to local needs¹³.

The role of the voluntary sector, carers and the wider community is a key part in these national and local plans. For example, 'peer and voluntary sector support' forms a key part of the overall Dementia Care Pathway, as specified in the strategy. The impact assessment, which accompanied the strategy, also makes clear that no one agency can achieve the changes outlined, adding that the NHS and local government need to work together with the not-for-profit and voluntary sector in order to do so. More recently, the government-funded Dementia Friends initiative, led by the Alzheimer's Society, has underlined the role of voluntary and community support in meeting the challenge of dementia.

2.3.3 The role of volunteering and informal care

Volunteering and informal care are recognised for their ability to help mitigate the rising costs of health and social care and also to bring other benefits, such as building relationships

⁹ DoH, 2010

¹⁰ Care Quality Commission, 2014; Dewing and Dijk, 2014; Bridges and Wilkinson, 2011; Cowdell, 2010

¹¹ DoH, 2009

¹² DoH, 2012

¹³ Essex County Council and partners, 2012

between services and communities and supporting integrated care¹⁴. This section gives a brief overview of this capacity to bring benefits, given the challenges it can entail, particularly in the context of dementia care. To give some perspective in regard to numbers of people involved: recent estimates suggest there are around 5 million informal carers in England, compared to 3 million volunteers in health and social care and 1.4 million paid employees in the NHS workforce¹⁵.

Volunteering

Various organisations have attempted to quantify the value of volunteering. Most relevant here is an estimate that, in mental health trusts, the financial value of volunteering was an average of around £500,000 a year¹⁶. This was calculated by applying a notional, median, hourly wage to the sum of hours of volunteer work in the trust. The figure does not, therefore, take account of the wider benefits of volunteering. A more recent Kings Fund report into volunteering¹⁷ finds, for example, that volunteers improve patients' experience of care and support in hospitals by bringing a more human dimension. The same report also cautions against placing too much emphasis on the capacity of volunteering to save money, suggesting that doing so will "backfire and lead to cynicism and disengagement"¹⁸.

In regards to volunteering in dementia, one set of challenges comes in the ability to recruit sufficient numbers of people to meet growing needs. Health and social care organisations involving older people are not among the most popular of options for formal volunteering¹⁹ in England. Instead, organisations involved in sports, hobbies and children's education occupy the top slots²⁰. Distinguishing between the overlapping categories of 'health and social care' and 'older people' clarifies formal volunteers' preferences further and indicates that although this is a minority area, it is still one which attracts substantial numbers. Around 27% of regular formal volunteers (2.9 million people) were engaged in 'health disability and welfare organisations', according to calculations from the National Citizenship

¹⁴ McNeil and Hunter, 2014; Naylor et al., 2013

¹⁵ Naylor et al., 2013

¹⁶ Teasdale, 2008

¹⁷ Naylor et al., 2013

¹⁸ Naylor et al., 2013, p.12

¹⁹ Formal volunteering is commonly understood as giving regular unpaid help through groups clubs or organisations to benefit people or the environment. This is in contrast to informal volunteering, which is giving regular unpaid help as an individual to people who are not relatives

²⁰ Cabinet Office, 2013

Surveys, which ended in 2011²¹. The category of 'older people' attracted a smaller proportion of formal regular volunteers, at around 16%, or about 1.9 million people.

Figures for dementia volunteers are harder to come by but one recent report indicates that a third of the volunteers engaged in organisations providing social care services to adults and older people were involved with people with dementia and mental health needs. These estimates are based on an analysis of the 2010 National Minimum Dataset for Social Care²².

A second set of challenges comes in integrating volunteers into healthcare settings. These challenges are well summarised in the Kings Fund report, which while recognising the "huge opportunities for volunteering to help transform health and social care services", also cautions that the need "is to ensure that the system can make the most of these opportunities"²³. The report raises the issue, for example, of how volunteers might feel about giving their time in an environment of increased private sector provision. It also says that financial pressures are bringing to the fore concerns about volunteering acting as a substitute for existing paid employment rather than a complement to it.

Informal care

There are approximately 670,000 primary carers caring for people with dementia and it is estimated they save the UK economy £11 billion annually²⁴. In contrast to formal volunteering, informal care is often less about choice and more about responding to a perceived need or fulfilling a sense of duty. Attracting people to informal care is not, therefore, the challenge. Rather, it is supporting those who find themselves in a caring role. This situation is recognised in the emphasis on support for carers in the National Dementia Strategy and its Essex equivalent. These facts that these carers are often older people themselves further underlines the need for support. In Essex, of the 10% or residents who provide informal care to relatives, friends or neighbours, over half are over 50 years old²⁵. Older carers for people with dementia thus fall into two overlapping areas of current policy

²¹ Naylor et al., 2013

²² Hussein, 2011

²³ Naylor et al., 2013, p.vii

²⁴ Alzheimer's Society, 2014

²⁵ Essex Insight, 2013

concern: addressing isolation and healthy ageing among older people; and meeting the challenge of dementia.

In conclusion, it is important to recognise that while informal care and volunteering can offer great benefits in addressing the health and social care needs of the UK population, they can also entail certain challenges. Among the most prominent challenges associated with informal caring is the need to combat physical and mental strain among carers; and key among the challenges of formal volunteering in dementia care is overcoming the barriers to volunteers operating effectively in healthcare settings.

3. The Evaluation

The evaluation was conducted between March 2014 and March 2015 and comprised the following steps, which are explained in detail below:

- Background documentary research
- Literature reviews
- Key informant discussions
- Semi-structured interviews with current and past Dementia Buddies, relatives/carers of patients currently or previously subscribed to the scheme, clinical and support staff on the two wards piloting the scheme
- A survey of volunteer buddies who had just joined the scheme
- Thematic analysis of the data gathered through the interviews
- Collation and presentation of all findings

3.1 Evaluation Approach

This evaluation is based on theory-driven inquiry. This type of evaluation looks not only at whether the intervention works but it also considers how it works (or fails to work). It is concerned not just with whether the outcomes are achieved but it also considers the mechanisms or processes that enable the intervention to work, and the conditions which promote or hinder success.

Ideally, a theory-driven evaluation involves the ability to design or modify the intervention, as part of the evaluation. A theory of change²⁶ approach recommends that the design of an intervention proceeds by identifying the ultimate goals and intermediate outcomes needed to achieve those goals, and then selecting an intervention which has a proven record in this context²⁷. The 'record' is established by the existence of research which has demonstrated a similar intervention working in a similar setting, and/or which identifies the causal process between the intervention and its goals.

Theory-driven evaluation in healthcare

The argument that theory-driven inquiry is appropriate for evaluating health care systems and their complex settings has been gaining ground over the last 15 years (for example, Marchal et al., 2012; Sturmberg and Martin, 2009, Hearne et al., 2003; Barnes et al., 2003; Glouberman and Zimmerman, 2002). Such studies build on well-recognised applications of similar approaches in areas such as community care and education, and on the development of theory-driven inquiry in evaluation more generally (Pawson and Tilly, 1997; Weiss, 1997; Connell et al, 1995; Chen and Rossi 1987, 1983).

In the case of the Dementia Buddies, however, the intervention had been designed and the pilot was underway by the start of the evaluation. Nonetheless, the researchers were able to use a theory-driven approach to guide the evaluation. In particular, this meant, the first step was to identify what those individuals involved in designing and piloting the intervention envisaged its aims to be. The research team supplemented this with a thorough review of the most relevant and up-to-date academic research to establish current knowledge about the link between similar interventions and their outcomes.

The next step was to establish ways of assessing whether, in practice, the goals were being achieved and to identify which factors might be enabling or hindering that process.

This research agenda, the small scale nature of the Dementia Buddies pilot, and the stated aims of the scheme lent themselves to a qualitative approach to this assessment process. Semi-structured interviews with clinical and support staff, carers of people who were on the Buddies Scheme and the buddies themselves formed the main part of the research. After

²⁶ 'Theory of change' is one type of the bigger category 'theory-driven evaluation'. Other types of theory-driven evaluation are: programme theory evaluation and realist evaluation (see box above for examples of this literature).

²⁷ Kale and Lumley, 2012

going through appropriate ethical and risk approval processes, the research team conducted 20 interviews between July and December 2014. We also carried out a brief survey of 13 buddies, gathering information on their age, gender and reasons for volunteering. By interviewing key staff and reviewing relevant documents, we were able to understand the expectations behind the Dementia Buddies scheme and how it was working out in practice. The subsequent interviews with relatives/carers, staff and buddies enabled us to add their perspective to this picture. We were able to ascertain, for example, whether the Dementia Buddies was achieving the objectives identified and whether it was, perhaps, having unintended or unforeseen consequences. We were also able to explore whether particular factors seemed to be helping or hindering this process. Where they help the process, we term these factors 'enablers'. However, it cannot be assumed that these enablers will necessarily apply to other dementia buddies schemes. Rather than make generalised assertions, the value of this research, therefore, is to provide a list of areas to consider when introducing a comparable scheme in a similar setting.

3.2 Background Research and Literature Reviews

The background research fed into our understanding of the evaluation's context, which is covered in section 2, above. It consisted of reviewing a large number of relevant documents, reports and websites, as well as newspaper and journal articles. This included a review of relevant literature on health and social care and volunteering.

We also undertook a review of literature on interventions to support the care of people with dementia. A summary of this review is presented in the Appendix. It helped us to establish current knowledge about similar interventions and their outcomes. It was clear from the review that support for carers is a key aim and outcome of many interventions in the context of dementia care. The interviews with key informants similarly demonstrated that support for carers is a central aim of the Dementia Buddies scheme. This therefore led us to place particular emphasis on the impact on carers in the evaluation.

3.3 Interviews and Survey

We started the research process by having discussions with three key informants: the Dementia Buddies scheme leader and the senior sisters from Summer and Spring. This was

to ascertain their views on the aims of the scheme, as well as background information about how it was operating. We also discussed the structure and requirements of the evaluation at this time.

Following this, we conducted 20 semi-structured interviews with: current and past dementia buddies (n=4); relatives/carers of patients currently or previously subscribed to the scheme (n=7); and clinical and support staff on the two wards piloting the scheme (n=9). The person who set up the scheme also operates as a regular dementia buddy so was able to contribute information from this perspective, as well as from her role of leading the scheme. The purpose and process of the interviews is detailed in sections 3.3.1 to 3.3.3, below.

We also conducted a brief survey of newly recruited buddies, which attracted 13 responses. It asked basic demographic questions, such as gender, age and religious affiliation, as well as an open-ended question, 'What led you to volunteer as a dementia buddy?' This question deliberately avoided phraseology such as what people 'get out of' buddying or the 'rewards' of buddying, to enable responses which do not immediately seem to fall into these categories. This reflects symbolic/sociological models used to account for volunteering behaviour²⁸.

3.3.1 Interview participant recruitment

We recruited buddies for interviews via the buddy survey, which included a question asking whether those concerned would be happy for a researcher to contact them at a later date to arrange an interview. The scheme leader helped in this process by making contact with other candidates and asking them if they would be willing to participate in the evaluation. We recruited relatives/carers in two ways: via senior nursing staff, where the patients concerned were currently on a ward; and via the person leading the buddy scheme, where the patients concerned were no longer on the ward. In the former case, one of the researchers attended a regular carers' meeting to introduce the research and request interview participants. In the second case, the scheme leader made contact with candidates and asked them if they would be willing for the researcher to get in touch.

²⁸ Wuthnow, 1991

3.3.2 Interview process and rationale

The 20 interviews were carried out between July and December 2014. They typically lasted for between 30 minutes and an hour. Sixteen were face-to-face interviews and four conducted by phone, for the sake of the interviewees' convenience. The majority of interviews were conducted at the hospital but two took place in the participants' homes. All interviewees were fully briefed about the research prior to interviews and agreed consent forms, in line with ethical requirements. The interviewer asked open-ended questions designed to elicit participants' views on the purpose of the scheme, their personal experience of it, and its strengths and weaknesses. The interviewer took the lead from the interviewees regarding the emphasis they put on who and how the scheme impacts. This style of interviewing mitigates against the tendency for pre-existing assumptions about the subject of research to shape research findings. It is therefore well suited to the in-depth examination of individual experience, attitudes and reactions to interventions among small numbers of participants.

3.3.3 Analysis

The interviews were recorded and later transcribed. We analysed the interviews using several rounds of thematic analysis, during which we identified common threads between and among the interviews. The findings from this process are detailed in section 4.

Findings from such research are not directly generalisable, as they are based on small participant numbers and are context-dependent. However they serve as a useful tool for designing larger-scale quantitative studies, helping to determine, for example, appropriate research or survey questions. They can also make a useful contribution to identifying best-practice approaches applicable in similar contexts, particularly where they are considered alongside other comparable studies.

4. Findings from the Survey and Interviews

This section describes the impact of the scheme on those involved: the carers/relatives, the patients, the clinical and support staff and the buddies. For each group, the description of impacts is preceded by a brief summary section. To protect our research participants, we have anonymised all direct quotes and arbitrarily assigned genders to people, which may or

may not reflect their actual gender. This section refers at various points to other literature which corroborates our findings. Where this is literature on comparable interventions, it is covered in the summary literature review in the Appendix.

4.1 Impact on Relatives/Carers of People with Dementia

On the whole, interviewees were positive about the impact of the dementia buddies on relatives/carers. The benefits they talked about can be grouped into the following categories, each of which is discussed in more detail below:

- Time to go on holiday, catch up with chores, pursue hobbies and interests, attend to own health and fitness
- Helping avoid social isolation
- Relieving emotional strain brought by caring
- Moving on from being the 'main carer' in a guilt free manner
- Giving time out from caring due to a trusted person keeping a watchful eye
- Raising the possibility of themselves or their friends/relatives volunteering in a similar role

The interviews also revealed some factors which undermine these benefits. These are:

- Belief on part of relatives/carers that a watchful eye is needed, suggesting a lack of underlying trust in staff
- Buddies not being available at times which suit relatives/carers

These views come mainly from six relatives of patients who had been buddied and one relative hoping to join the scheme, talking about their experiences of the scheme. Of those people, three had relatives who had been buddied while on Summer Unit, one while on Spring and two while on both units. Clinical and support staff, also offered some opinions on the effect of the scheme on relatives, and although these are less direct accounts than those from the relatives themselves, they do corroborate those views to the degree that several of the same themes come up and no members of staff had views that directly contradicted what the relatives said, although two said they felt unequipped to comment on the impact on relatives.

4.1.1 “Me time” - holidays, chores, hobbies and health

Five of the relatives we interviewed specifically valued the scheme for giving them a break, and two said that they had initially joined the scheme in order that they could go away for a few days. The relative hoping to join the scheme also specified wanting to go on a family holiday as the main reason for joining. Some relatives value the scheme giving them a break for the more mundane opportunity to “catch up with other things”. The clinical staff also talk about the importance of the scheme in giving carers a break. When relatives are asked to expand on how the scheme gives them a break, they mention shopping and housework but also talk about addressing their own physical and mental health needs. One relative says before joining the scheme, they were visiting their spouse every day and were experiencing health problems. They say the scheme gave them a chance for a break, adding:

“I don’t know where I would have been without them [the buddies].” – Relative of a person in buddy scheme

Other relatives continued to visit every day after joining the scheme but felt able to take a morning or afternoon off. Another relative talks about the “need to make a life for myself”. Closer discussion reveals that this entails re-joining fitness and hobby classes. This relative also details a number of health problems. One relative, a very frequent visitor to the ward, says that they want the buddies to visit in the evening (an option not available at the point this was written). They say that if an evening visit were possible, they would be able to have some “time off”, which they have been advised to do. They add that they have difficulties sleeping due to worrying about their spouse.

4.1.2 Avoiding social isolation

The risk of social isolation comes up when a relative describes the degree to which the ward has become their social world. This is expressed in a positive way: they enjoy knowing the staff and other carers/relatives but they also mention that reliance on the ward for social contact puts them in a precarious position. They express this as concern about what will happen to them when their spouse dies or is moved to another hospital or care home.

The tendency for relatives to become isolated also comes up in interviews with clinical staff.

One nurse says:

"I think a lot of the relatives come here to talk to us, to talk to the other relatives purely because their life has now stopped as they knew it and this is it." - Member of clinical staff

Another nurse explains that if patients are bed-bound and relatives spend hours with them they can begin to feel isolated from other social contact. The nurse explains that the buddy scheme allows carers to overcome this. She adds that, for the same reason, it's good to see buddies focus not only on the patients but on the carers too, when they are there together.

4.1.3 Lessening the emotional strain

One relative talks about the buddy visiting alongside them, rather than instead of them. This person says the scheme enables them to "stand back a bit, rather than being the one that takes it all". They describe observing the interaction between the buddy and their spouse and, in this way, being able to get a different and more dispassionate perspective. They say this "seem to lighten the visit" by deflecting pressure from themselves.

Other relatives talk of seeing their spouse smiling at the buddy. One says:

"That says it all really for me, if he's smiling". - Relative of a person in buddy scheme

In these cases, the evidence of a spouse's happiness gives the carer pleasure and validates the scheme's worth. These comments are part of a more general theme of the scheme benefiting patients and thereby having a knock on effect on relatives/carers. One relative, who was not able to visit often themselves, says that they valued the Buddies scheme for the interaction it offered. This person says dementia took his relative "into his shell", "made him withdrawn" and that the Buddies scheme offered a chance to connect with the "real

word". This was something they felt their relative needed but that the clinical staff were too busy to provide and they could not give themselves.

4.1.4 Letting go and relieving guilt

One older relative says that the car journey to the ward is difficult in bad weather and, thanks to the buddying scheme, the pressure to embark on the journey at such times is relieved. This has wider implications in regards to the health and safety of older people, who may put themselves at risk in order to meet what they see as the obligation to visit a friend or relative in hospital. One relative talks about the guilt associated with a spouse having to go into hospital at all, and the implication that they have failed somehow in their duty of care. This is backed up by one of the clinical staff who says some relatives feel they have to be there all the time but if a buddy can replace them occasionally, "they feel less guilty".

Others relatives describe feeling rejected when their spouse does not allow them to feed or clean them during visits. The non-clinical, caring role of buddies goes some way to address these difficulties. In the words of one relative:

"It's strange but you feel, well, they [the buddies] are relieving me of some of the stress and as soon as you accept that... You have looked after them for so long but it's letting go really. I still do some things." - Relative of a person in buddy scheme

As with the relatives, clinical staff mention the friendly nature of the relationship between buddies and patients, saying that it enables relatives to step back a little. This is backed up by other research that talks of carers transitioning from 'conductor' to 'second fiddle' under similar circumstances²⁹. As one nurse says, this becomes easier where there is trust:

"It is reassurance that someone has given up their time to come and be with someone in hospital. I don't think it is just about a break [for the relatives]. I think it's nice that these people are doing it out of the kindness of their heart and if it

²⁹ Lowson et al, 2013

was one of my relatives, I'd think, these people are coming in here through nothing else but kindness.” - Member of clinical staff

4.1.5 A trusted person to “keep an eye”

Two relatives value the buddies for “keeping an eye” on the person they care for. One says:

“I just think, if something was wrong or they [the ward staff] spoke to my husband not right, they [the buddies] would probably tell me. I would think so.” – Relative of a person in buddy scheme

The value these relatives place on the watchful presence of a buddy could simply reflect a more cautious character on their part, but it is perhaps relevant that, in both cases, the patients concerned had spent time in Summer unit and the relatives expressed some reservations about the clinical staff. In one case, the reservation was about the variety in the commitment levels of clinical staff: “some people take it as a job and some more as a vocation”. In the other case, the misgivings were more pronounced, but again applied to only one or two clinical staff. It was beyond the remit of this evaluation to investigate whether those misgivings were justified or not and no direct allegations of a kind which warranted follow up after the interviews were made. The point here is to highlight that in these cases, relatives both exhibited reservations about the staff and valued the Buddies scheme for its capacity to provide a watchful eye over the person they cared for. This raises the issue of what impact different conceptions of the scheme’s benefits might have on how it plays out in practice. In particular, if staff feel the scheme is there to “keep an eye on them”, how might that make them feel and, in turn, impact on the success of the scheme? The evaluation sheds some light on this question and section 5 takes up the point.

The fact that some relatives suggest that the buddies are useful in keeping a watchful eye also implies a level of trust in the buddies themselves. One relative describes them as:

“Absolutely lovely, I can’t speak too highly of them [the buddies]” – Relative of person in buddy scheme

Another relative describes the buddies as “brilliant” and “one big benefit”. One talks admiringly of a particular buddy calming a patient (not her own relative) who is often agitated. The interviews suggest that trust in the buddies is widespread among the relatives and is engendered in three ways: meeting the person who runs the scheme; meeting the buddies themselves; and seeing the buddies ‘in action’ with patients.

Where relatives do criticise the Buddies scheme in any way, it is about buddies not being able to come in when they would like them to. The relatives value the passion, enthusiasm and caring nature of the person running the scheme and the fact that this individual has personal experience of caring for someone with dementia. They also value talking to the buddy who sees their relative and being able to tell them about the patient’s life history, interests and likes and dislikes (although not all relatives have done this). They are also reassured both by phone calls they get updating them after visits by buddies and by looking at the book in which visits are recorded, which enables them to read about what happened.

4.1.6 From carer to volunteer

As part of the interview and where appropriate, the researcher asked relatives whether they would consider buddying themselves. Of the six people asked, four said they would consider being a dementia buddy themselves, referencing their accumulated experience and knowledge of dementia as a result of their caring role. Whether in practice these people do go on to buddy is another question but knowledge of the scheme is likely to spread beyond those most closely involved with patients and, where relatives have a positive assessment, this may encourage others to consider volunteering in a role concerning dementia. It is also relevant to note that several of the buddies have experience of caring for a family member with dementia and some cite this as a reason for their involvement (see section 4.4.1).

4.2 Impact on Patients

Overall, reports of the ways in which the scheme benefits patients are a stronger theme in interviews than reports of it not benefitting them. The types of benefit can be grouped into

circumstantial and observational. The former are benefits which accrue from the scheme addressing potential deficits in other provision. These are:

- Sustained one-to-one, non-clinical, friendly attention
- Attention of this kind for patients who do not want or are unable to join group activities and/or go to communal areas
- Attention of this kind for patients who rarely, if ever, have visitors
- Less need to demonstrate immediate impact due to the voluntary nature of the scheme and a resultant reduction in pressure on patients to respond

Observed benefits are those which interviewees say they can observe in patients when a buddy visits. These are:

- Patients being more verbally communicative
- Eyes lighting up, laughing, smiling
- Relaxing, calming down, becoming less agitated

Finally, various reasons that undermine patients' capacity to benefit from the scheme are mentioned. These are:

- Lack of capacity to benefit at particular times or among particular patients due to individual factors
- Lack of capacity for patients *in general* to benefit due to health status and/or medication
- The organisational challenges of aligning buddies visits with times patients are most receptive to them

In assessing the impact on patients, this study relies on interviews with clinical and support staff, buddies and relatives. This has some drawbacks, not least that these are not direct accounts from the patients themselves. Unfortunately, this would have presented considerable ethical as well as practical challenges. In addition, dementia takes many forms, and the form of dementia, as well as how long an individual has experience of it, will affect their response to buddying. Also, even where individuals have the same type of dementia, one person's experience of it is likely to differ from another's. Finally, an individual's response to a buddy also depends on many other variables, such as their mood, their personality, the medication they are on, any other medical conditions they may be suffering

from, as well as the buddy's manner and approach. Nonetheless, the interviews yielded some compelling accounts of perceived benefits and impediments on the part of patients, which are backed up by other research. These are discussed in more detail in the next sections.

4.2.1 Circumstantial benefits – one-to-one, non-clinical friendly attention

One of the main themes which came through, particularly in interviews with the clinical staff, was the idea that the Buddies scheme gives patients additional one-to-one attention of a non-clinical kind. As one member of clinical staff sums up, buddies are a replacement for friends in the patients' lives, giving a different type of relationship than that with either family members or staff. One nurse says: "We are doing all the things you have to do but not the nice, loving things. There's no quality time." This idea that the clinical staff lack the time for things, such as just sitting with a patient and holding hands for a while, or talking to them about their past life, is commonly expressed. Mealtimes are one occasion when the clinical staff say they can do this, and many talk about trying to fit it in at other times where they can, but it is this kind of contact which they see as beneficial in the Buddies scheme. Other research has drawn attention to the ability for volunteers to provide hospital patients or care home residents with this kind of interaction³⁰. Just sitting and holding hands also makes available the therapeutic benefits of touch, which other literature shows to be of value in agitated Alzheimer's patients.³¹

Relatives also comment on how busy the clinical staff appear to be, saying, for example, that they have "no time to sit and talk". Another relative says that they "got the impression that staff had great demands on their time" and the Buddies scheme "would free them up". Another theme in the interviews is that the buddies offer something distinct from the occupational therapists (OTs) or activities coordinators. The Buddies scheme is designed around a model of one-to-one attention, whereas the OTs and activities coordinators are perceived to focus on group activities and/or on activities which those who are bed-bound cannot attend, as they take place in another room. Bed-bound patients, in particular, may lack the social contact available in communal spaces on the ward or from engaging in the

³⁰ For example Tanner and Brett, 2014, Naylor et al., 2013

³¹ For example Hawranik et al., 2008

group activities. This is an example of the more general point that volunteers can fill gaps in provision – an observation made in other studies of volunteering in healthcare³².

One member of clinical staff sees advantage in the informal, voluntary nature of the Buddies scheme because, she feels, it is less bound by having to demonstrate results. “They’ve got no obligation to see if this person responds to holding the ball or whatever... Obviously the OTs have a job to perform, whereas these people haven’t. [The buddies] don’t have a report to fill in or anything...OTs have to prove themselves. These people don’t have to. That’s the difference. That’s just my opinion, my perception.” The difference this makes to the patients is that the resulting interaction can more relaxing:

“If you’ve got someone whose job depends on demonstrating that this particular thing worked then they are maybe going to be feeling they have to push the person to do something.” – Member of clinical staff

The idea that the activities coordinators, likewise, have to demonstrate effect came through in another staff interview. The pressure on paid staff to demonstrate effect and its influence on the degree to which they encourage patients to take part in a particular activity is also mentioned in other literature.³³ Our interviews also reveal a perception that there is some tension between the buddies, OTs and activities coordinators over what some see as competing objectives. This is covered in section 4.3.4 more fully.

One group of patients who particularly benefit from the Buddies scheme, according to clinical staff, are those who rarely or never have visitors. The Buddies scheme gives such people an opportunity for sustained, one-to-one, friendly attention, which they might otherwise lack. One member of clinical staff describes a buddy visiting such a patient and managing to learn aspects of their history, which the staff members had been unaware of. This enabled staff to respond to the patient in a more person-centred way.

³² Naylor et al., 2013

³³ Tanner and Brett, 2014

4.2.2 Observed benefits - verbal and non-verbal expressions of enjoyment and calm

Many of those interviewed said they felt the patients enjoyed having a buddy and, when questioned more closely about why, people refer to the same observations. These can take a verbal form - being more chatty or talkative. For example, one nurse says:

“They [the patients] are smiling and saying things, and you’ll hear them say things they haven’t said in months.” -
Member of clinical staff

In cases where patients are not verbally communicative, clinical staff and relatives describe seeing a patients “eyes light up” or them smiling when the buddy arrives. The buddies describe patients affectionately squeezing their hands while they are talking to them. One says: “When you go and talk to them, you feel they are happy and their mood changes.” Another buddy says that even where patients seem unresponsive, “they still hear you and feel you and they try and communicate with you”.

Clinical staff and relatives also describe patients who were formerly agitated visibly calming down or relaxing in the presence of a buddy. One member of the clinical staff says:

“I’ve seen them [the buddies] calming someone down. The reassuring voice, even if they can’t understand what they are saying, because that is what some of our clients want. They just want someone sitting next to them. They just want someone to hold their hand.” - Member of clinical staff

Another staff member suggests that the calming down may, in some cases, be about relieving the patient’s sense of boredom. Another reports that in regards to a particular patient, she considers this calming down to be a long-term effect, saying the patient’s mood has improved in general over the period since she first started seeing a buddy. Another says that the buddy scheme has marked benefits for one particular patient (possibly the same person): “She thrives on it. She is so chilled after it. She loves it. She is smiling, laughing, and afterwards more loving towards us, even.”

Some relatives are quite specific about what they believe their spouse likes about the Buddies scheme. In these cases, it should be taken into account that the person reporting the effect knows the patient extremely well. Conversely though, it may be that they are more predisposed to see a beneficial effect in a person they love. One person says that their spouse, “likes to see people around, likes people talking to him and showing him things”. Another reports, in a more objective, evidence-based way, that their spouse talks to the buddy about things that happened in their past that they haven’t talked about for some time and that the relative knows to be based on fact.

Another type of impact is raised in interview with one buddy – a tailored effect that is possible only with a one-to-one approach, such as the Buddies scheme. The buddy concerned talks of a patient evidently preferring the peace of their own room but not wanting to feel alone there, something which having a buddy makes possible: “When you see her in her own room, she is smiling, she is happy, you can talk to her. She is interactive. But when you see her in the hallway, all she does is moan and swear. She is just not happy. She is happier in her own room because of all the noise and stuff.” In a similar vein, one relative talks about his spouse liking the buddies because “they get talked to rather than talked around”. They say their spouse likes “someone paying attention to her, one-to-one”. This exemplifies the common sense point that simply being around others is not the same as meaningful interaction with other people.

4.2.3 Reasons for not benefiting – from individual to ward-level circumstances

One reason that came up often in interviews, for why patients might not benefit from the scheme revolves around the variety in individual patient experience, as discussed in the introduction to this section. The circumstances of some patients may mean that they are not predisposed to benefit from the scheme at all, or at particular times. This might be due to interconnected factors such as their medication, their personality, and the way that their ill-health is manifesting overall, or at that time.

It was noticeable, however, that what to some interviewees was a point about the differential experience some patients might have of the buddies, for other interviewees extended into a more overarching point about patients *in general* not being able to benefit

from the scheme. It was also notable that reports of this nature were confined to one or two of the staff on Summer unit.

When asked whether the patients benefit from the Buddies scheme, one member of staff replies:

“Well I don’t really think they [the buddies] do a lot for the patients, because of the clients we have.” – Member of staff

This individual goes on to say that “this lot” of patients are particularly unable to benefit from the buddies visits. When asked whether some buddies get a better response from the patients than others, they reply, “no it’s just the clients, I think it’s just the clients”. They add, “it’s a shame because they [the buddies] want to do good”. They recommend that the buddies, “go and see someone that can do stuff and remember” and they give the example of people with a heart condition or physical illness.

Some clinical staff attribute any failure for the scheme to benefit patients to features of the way it is organised. Chiefly, this is about the combination of buddies being on the ward only for relatively short periods of time and the difficulty of making sure the buddy arrives at a time when the person they are coming to see is awake and in a receptive mood. According to some staff and buddies’ accounts, on occasion, a buddy comes in, possibly after a journey that has taken some time, only to find that the person they are supposed to be buddying is asleep or does not want to see them. While this may not be a problem for the patients, since, as one member of the clinical staff puts it, “patients make it clear when they want to be left alone”, it may be frustrating for the buddies. Two interviewees say that staff such as the activities coordinator are in a better position to respond to these changing circumstances because they are in there all day and so can come back later if a given person is asleep. The problem of finding the right time to visit is among the reasons one buddy gives when explaining why she decided to quit. “If I get given a new person, I speak to staff and ask when it’s the best time to see a person. Even when I do that and phone up and go in

for a visit and then they are asleep and you can't wake them." Another buddy also describes a similar incident as a "wasted journey".

4.3 Impact on Clinical and Support Staff

As with the relatives/carers, we were able to ask clinical and support staff directly about their experience of the Buddies scheme. This is the source of most of the material in this section, although it is supplemented with comments from relatives/carers and buddies. Comments about the scheme's positive impacts on staff fall into the following categories:

- Satisfaction from patients getting additional one-to-one, non-clinical, friendly attention
- A reminder and supplement for person-centred care and compassion
- More relaxed and calmer patients who are easier to interact with

There was also some evidence of staff doubting the benefits of the scheme, although this was a more minor feature of the interviews. It fell into two main types:

- Tensions over buddies roles
- Lack of trust and respect between staff and buddies

4.3.1 Satisfaction at seeing patients get one-to-one, non-clinical, friendly attention

A common theme in interviews with clinical staff themselves, as well as buddies and relatives, is the busy schedule of the clinical staff and the consequent squeeze on the time they have to give patients one-to-one, non-clinical attention. Many of the staff express regret about this situation, illustrating that they do not lack the desire to relate to patients in this way, so much as the time. By extension, they are pleased to see the patients getting this kind of attention from other sources.

As one member of clinical staff says:

"It's nice because you think, 'I can't get them [the patients] to do that'. They've got the time to sit there and say, 'do you like this picture and do you remember this'. It's nice that they [the patients] are engaging in it." – Member of clinical staff

Another says, “It’s a shame we haven’t got time to sit there and look through pictures with them, it is a shame we can’t do that for long.” These sentiments are summed up by another member of staff who talks approvingly of the Buddies scheme giving the patients “what they need”.

These kinds of attitudes suggest that the Buddies scheme gives compassionate yet busy clinical staff some comfort that this aspect of patient care is being addressed.

4.3.2 A reminder and supplement for person-centred care and compassion

One member of clinical staff suggests that the Buddies scheme acts as a useful prompt “to remind us to be compassionate – we all have bad days”. She adds that having the buddies around helps “keep staff on their toes, another pair of eyes watching you”. This is in the context of an interview where the same member of staff refers to clinical staff’s fondness for patients. She ascribes this to the relationship built up when you care for someone over time and, she talks of the “void” created when a patient passes away.

The interviews overall indicate varying opinions about the levels of compassion care shown by clinical staff. The most negative opinion is that where there is any lack of compassion, it manifests either as an occasional dip in the approach of some clinical staff or features more regularly among a very small minority of staff.

Various interviews also draw attention to a positive feature of the Buddies scheme: that during buddy visits, details of the patients’ lives or interests come up. One member of clinical staff describes a particular incidence of this happening, saying that, as a result, staff were able to respond to an interest the patient had which they had not formerly known about. This chimes with other research which points to improved relations between staff and patients as a result of volunteer input³⁴. Other interviews also cite particular instances of buddies getting patients talking about their past lives and thereby giving those patients an opportunity to express their individuality. This feeds into the type of person-centred care championed by Tom Kitwood³⁵. The potential for time-pressed ward-staff to enhance their

³⁴ Tanner and Brett, 2014; Naylor et al., 2013

³⁵ See for example Kitwood, 1997, *Dementia Reconsidered: the person comes first*.

focus on person-centred care as a result of volunteer involvement in hospitals is also remarked on in other literature³⁶.

4.3.3 More relaxed, calmer patients

As discussed in the section about the impact on patients, the idea that buddies visits can make patients more relaxed and calm was widespread. Where this happens, it can have a knock on effect on staff, making it easier for them to interact with the patients subsequently. One member of clinical staff mentions a particular example of this, in which she was able to deflect a patient's tendency to aggression by talking to her about the fact that she'd had her nails painted by a buddy. Another comments that after buddies have visited patients are "more loving" towards the staff.

Two members of staff also mention that, they feel, this effect endures beyond the immediate aftermath of a visit. One says that after buddies have been "the patients seem to be in a good mood, a relaxed mood" and she adds the example of a particular patient, saying, "I noticed before that he is very unapproachable but lately I have noticed he has changed - before there was nothing you could do." Another member of staff talks about buddies engaging with patients who are demanding attention from staff, for example, by being restless or aggressive. In this situation, she sees an advantage in the buddies engaging these patients, and thereby freeing staff up to attend to other patients.

4.3.4 Tensions between buddies and paid staff

Talk of tensions between the buddies, and the occupational therapists and activities coordinators is a common feature of several interviews, being mentioned in five staff interviews and three buddies interviews. The existence of these kinds of tensions between volunteers and paid staff are also highlighted in other literature³⁷. One member of staff sums up the situation by saying, "sometimes I get the feeling that the OTs think the buddies are stepping on their toes". Similarly, some of these members of staff mention overlapping roles as a source of tension between the buddies and activities coordinators. In this context, there is also reference to the fact that the buddies are volunteers, whereas the OTs and activities coordinators are paid members of staff. Despite reference to these tensions,

³⁶ See Dewing and Djik, 2014

³⁷ For example Tanner and Brett, 2014; Naylor et al., 2013

interviewees also remark that the roles should be seen as complementary rather than competing, because, for example, the OTs and activities coordinators tend to concentrate on group activities, whereas the buddies role is more like that of a friend, giving attention and companionship at an individual level. This leads one member of nursing staff to comment, “I don’t know why they can’t just work in unison”.

Three buddies also say that from their perspective, relations between themselves and staff in general differ between the two wards. One buddy describes this as feeling “more comfortable” on one ward than the other; another talks of not finding the staff on one ward “quite as nice” as on the other; and a third talks of a “them and us” feeling on one ward. In each case it is the same ward which is compared less favourably.

One member of staff also says that she felt one particular buddy had a tendency to overstep her role, implying to staff that they were not attending to patients adequately. In the member of staff’s view, staff were merely balancing competing requirements in an entirely appropriate and professional manner. The staff member described the problem as an exception to the norm of harmonious relations between the buddies and nursing staff and on the whole she was very approving of the buddies scheme.

The interviews also point to another set of tensions which are perhaps better described as between organisational cultures than between groups of individuals (although the two are related). These concern the difficulties in integrating a voluntary, small-scale, flexible scheme, such as the Dementia Buddies, into NHS systems. In one interview, a buddy describes what he experienced as difficulties on entering the ward (having to ring a bell as a result of not being given the door code). This created a sense of not being fully trusted and also having to disturb busy staff. Another interviewee talks of the steps and time entailed in organising training for volunteer buddies and the possibility that this might put some applicants off. (The latest model for training addresses this shortcoming, see section 2.1.1.)

The need to ensure patient confidentiality is another area which raises tensions in the context of buddying, and the interviews reveal various examples of this. One interviewee says that ward staff are not allowed to inform buddies before they come to visit if a

particular patient has been transferred to a care home and is, therefore, no longer available for visits. Two other interviews highlight a line which is difficult for buddies to navigate in this context: that between casual comment on how a patient is 'feeling' or 'getting along', as opposed to clinical discussion of their medical status. Where these discussions are with relatives, it is necessary that the relative is able to distinguish between the types of information.

4.4 Impact on Buddies

The researchers drew on the interviews and a survey results from 13 buddies for this section. As with previous sections, the most direct source of information is the buddies themselves, although interviews with staff also touched on this issue. The positive impacts can be grouped into two categories:

- Ability to turn personal experience into shared expertise (including for career purposes)
- Therapeutic and emotional rewards

The interviewees also mentioned some more negative impacts

- Feeling unwelcome or redundant
- Emotional strain

4.4.1 Turning personal experience into expertise

It is relevant to reiterate that the Buddies scheme leader set the scheme up as a response to their experience of caring for a family member with dementia. This individual describes wanting to do something about the situation they had found themselves in when their relative had dementia.

Experience of dementia in the family also features in the buddies surveys and interviews. Four of the 13 buddies who took part in the survey mention a relative in answer to the question, 'What led you to volunteer as a dementia buddy?'. Two of the buddies interviewed also say they were motivated to become buddies as a result of a family member having dementia. In addition, as mentioned in the impact on relatives/carers section 4.1.6, out of six relatives who were asked whether they would consider buddying themselves, four

expressed an inclination to do so, based on the idea of turning their experience into benefit for other people.

This experience can translate into a degree of expertise which, according to various interviews, is useful in the context of dementia buddying. People who have previously been around individuals with dementia are likely to be less shocked by some of the behaviours associated with the condition, such as aggression or sudden mood changes. The clinical staff mention that it is helpful if buddies know how to respond in this situation, picking up on warning signs so as to minimise personal risk and not being too upset if a person is aggressive or dismissive.

Other buddies are motivated in part by building on personal or previous work experience to develop a career in dementia care – this was evident both from the survey and one of the interviews with a buddy.

4.4.2 Therapeutic and emotional rewards

Buddies also identify other personal rewards from buddying, for example the simple enjoyment it brings. One of the interviewees also talks about a therapeutic effect: of buddying enabling her to work through the experience of losing a close relative to dementia. This buddy says that seeing the patients on the wards reminds her of some of the good times with her relative. In addition, being able to buddy someone but then walk away stands in healthy contrast to informal caring, which can become an all-consuming part of life. Buddying can enable individuals to gently let go of their own experience, while at the same time, helping others.

4.4.3 Some challenges of dementia buddying

The interviews also pointed to some of the challenges which buddies can experience. The various organisational difficulties stemming from integrating a volunteers scheme into the NHS are covered in section 4.3.4. These can lead to buddies feeling unwelcome or that they have had a wasted journey because they come in to see someone who is asleep or very unresponsive.

Some buddies also report emotional strain, such as the situation bringing back uncomfortable memories associated with caring for an older relative in the past (although not necessarily someone with dementia). One buddy also talks about her sadness at seeing a particular patient's condition worsen over time.

5. Conclusion

Comments describing the scheme's positive impacts on carers/relatives, patients, staff and buddies are a major theme of the interviews (see Table 1 for a summary). Among these, observations along the lines that the buddies offer a relationship characterised by informal, unhurried friendliness are particularly prominent. Although clinical and support staff theoretically have time for this kind of interaction, interviewees report that, in practice, it occurs less frequently than is desirable. The knock-on effect of the buddies being able to fill this gap is, relatives tell us, that they feel able to take a break, both from the time they spend visiting and the emotional strain of caring for someone with dementia. An important ingredient in relatives feeling able to step back is their trust in the buddies as individuals, as well as a belief that what they are doing is valuable. For patients who seldom or never receive visits, the presence of buddies is potentially even more rewarding, according to staff we interviewed, because in these cases, the buddies may be the only visitors offering purely friendly, one-to-one interaction that those patients get. Staff report that another positive repercussion of the buddies visits is that staff, too, feel reassured to see patients getting more of this kind of interaction. This not only makes these staff feel happier but it can also afford them extra time for their own duties. This effect is reinforced in cases where the buddies are able to calm agitated patients down.

However, the interviews did also reveal some contradictory views, albeit that these were in a minority. There was a sense among some clinical and support staff that the buddies are not needed. These views were more prevalent among those associated with Summer unit. The reasons given fall into three categories: that what the buddies offer is already available from paid staff; that the patients in general do not have the capacity to benefit from the kind of interaction the buddies offer; that all too often, individual patients are not predisposed to benefit from buddies visits. Where these feelings are present, our interviews

show that they are associated with other negative assessments. For example, rather than being reassured by the presence of buddies, staff can feel that their role is undermined. This, in turn, is perhaps at the root of some buddies telling us that they have felt unwelcome on the ward. A more defensive tone also comes through in some interviews with relatives. In these cases, buddies are valued for their ability to 'keep an eye', as much as to provide friendly company to patients. Under these circumstances, it follows that when relatives do allow buddies to give them a break from their own visits, they may not be as relaxed as they would if they felt a watchful eye was not necessary in the first place. The potential for this kind of negative circle of effects to develop is noted in comparable research. A study into the experience of carers, during hospitalisation of the person they care for, found that good communication between carers and staff can help avoid a 'cycle of discontent' building, in which carers become uncertain or suspicious, and, as a result act in a 'hyper vigilant' manner³⁸.

By drawing out both negative and positive assessments of the scheme's impact, the interviews helped us to identify some of the mechanisms behind its success or otherwise. In this context, 'success' consists in a positive assessment of the scheme by those involved and the related impact of that on its sustainability. This is in line with our approach to evaluation, which seeks not only to look at the outcomes of an intervention, but to understand the mechanisms behind them (see section 3.1). We have expressed these mechanisms in their positive form and so describe them as 'enablers'. They are as follows:

1. Organise the scheme in such a way as to maximise the individual capacity of patients to respond during a buddy visit, in particular to avoid them being asleep or adversely medicated.
2. Make sure all staff are 'on-board' in regard to the benefits of person centred care for all patients. Person-centred care should be uniformly respected and practiced in the setting.

³⁸ See Jurgens, 2012, also discussed in the Appendix

3. Ensure that the scheme complements current provision rather than competes with it. Paid staff should feel that this is the case. The way in which the scheme is introduced is important in this regard.
4. Training of buddies should explain and justify what might otherwise appear to be cumbersome requirements of NHS systems. Similarly, where possible, systems should be tailored to accommodate volunteer support. Training should also prepare buddies for the realities of engaging with people who have dementia.
5. Enable relatives to meet the person running the scheme, meet the buddies themselves, and see the buddies 'in action' with patients.

Our research shows an association between an absence or paucity of these enablers and negative assessments of the impacts of the scheme, which feed into one another. By contrast, where the enablers are present, the Buddies scheme has the potential to lead to a self-reinforcing circle of positive impacts (see Figure 1, page 5). As with the impacts, the enablers do not stand in isolation from one another, there is overlap and interplay between them. Finally, it would be problematic to assume that these enablers necessarily apply to other dementia buddies schemes in different contexts. The value of the research, in this regard, is to provide a list of areas to consider when introducing a comparable scheme in a similar setting, rather than to make generalised assertions.

Table 1: Summary of findings on positive impacts of the Dementia Buddies scheme and undermining factors, by group affected

Group	Positive impacts	Undermining factors
Relatives /carers	<ul style="list-style-type: none"> • Time to go on holiday, catch up with chores, pursue hobbies and interests, attend to own health and fitness • Helping avoid social isolation • Relieving emotional strain brought by caring • Moving on from being the 'main carer' in a guilt free manner • Giving time out from caring due to someone else keeping a watchful eye • Raising the possibility of themselves or their friends/relatives volunteering in a similar role 	<ul style="list-style-type: none"> • Belief on part of relatives/carers that a watchful eye is needed, suggesting a lack of underlying trust in staff • Buddies not being available at times which suit relatives/carers
Patients	<ul style="list-style-type: none"> • Get more sustained, one-to-one, non-clinical, friendly attention • Attention of this kind for patients who do not want or are unable to join group activities and/or go to communal areas • Attention of this kind for patients who rarely, if ever, have visitors • Less need to demonstrate immediate impact due to the voluntary nature of the scheme and a resultant reduction in pressure on patients to respond • Patients being more verbally communicative • Patients appearing to express pleasure by eyes lighting up, laughing, smiling • Patients appearing to relax, calm down, become less agitated 	<ul style="list-style-type: none"> • Patients not in a position to benefit due to individual-level circumstances, such as medication or sleep patterns • Patients as a whole perceived not to be in a position to experience positive impacts
Staff	<ul style="list-style-type: none"> • Satisfaction from patients getting additional one-to-one, friendly attention • A reminder and supplement for person centred care and compassion • More relaxed and calmer patients who are easier to interact with 	<ul style="list-style-type: none"> • Tensions over buddies roles • Lack of trust and respect between staff and buddies
Buddies	<ul style="list-style-type: none"> • Ability to turn personal experience into shared expertise (including for career purposes) • Emotional and therapeutic rewards 	<ul style="list-style-type: none"> • Feeling unwelcome or redundant • Emotional strain

6. References

- Alzheimer's Society, 2014. *Dementia UK Update*. London: Alzheimer's Society.
- Alzheimer's Society, 2009. *Counting the cost: caring for people with dementia on hospital wards*. London: Alzheimer's Society.
- Barnes, M., Matka, E., Sullivan, H., 2003. Evidence, Understanding and Complexity: Evaluation in Non-Linear Systems. *Evaluation* 9, pp.265–284.
- Bateman, C., 2012. *Research into practice: Volunteers improving person centred dementia care in a rural hospital: an intervention study* (master's thesis). University of Canberra, Australia.
- Bridges, J., Wilkinson, C., 2011. Achieving dignity for older people with dementia in hospital. *Nursing Standard*, 25, pp.42–47.
- Cabinet Office, 2013. *Giving of time and money: findings from the 2012-13 community life survey*. London: Cabinet Office.
- Care Quality Commission, 2014. *Cracks in the pathway: people's experiences of dementia care as they move between care homes and hospitals*. Gallowgate: Care Quality Commission.
- Chen, H.T., Rossi, P.H., 1987. The theory-driven approach to validity. *Evaluation and program planning* 10, pp.95–103.
- Chen, H.T., Rossi, P.H., 1983. Evaluating With Sense: The Theory-Driven Approach. *Evaluation Review* 7, pp.283–302.
- Clissett, P., Porock, D., Harwood, R.H., Gladman, J.R.F., 2013. Experiences of family carers of older people with mental health problems in the acute general hospital: a qualitative study. *Journal of Advanced Nursing*, 69, pp.2707–2716.
- Connell J., Kubisch A.C., Schorr L.B., Weiss CH, eds., 1995. *New approaches to evaluating community initiatives: concepts, methods and contexts*. Washington DC: The Aspen Institute.
- Cowdell, F., 2010. Care of older people with dementia in an acute hospital setting. *Nursing Standard* 24, pp.42–48.
- Crispi, E.L., Heitner, G., 2002. An Activity-Based Intervention for Caregivers and Residents with Dementia in Nursing Homes. *Activities, Adaptation & Aging*, 26, pp.61–72.
- Department of Health 2013, *Dementia: a state of the nation report on dementia care and support in England*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf [Accessed 25 March 2015].
- Department of Health 2012, *Prime Ministers challenge on dementia: Delivering major improvements in dementia care and research by 2015*. Available at www.gov.uk [Accessed 25 March 2015].

Department of Health, 2010, *Quality Outcomes for People with Dementia: Building on the Work of the National Dementia Strategy*. London: Department of Health.

Department of Health, 2009, *Living well with dementia: a national dementia strategy*. London: Department of Health.

Dewing, J., Dijk, S., 2014. What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia*. Available at: <http://dem.sagepub.com/content/early/2014/01/22/1471301213520172.full.pdf> [Accessed 25 March 2015].

Essex County Council, Southend-on-Sea Borough Council, Thurrock Council, NHS North Essex, NHS South Essex, North Essex Partnership NHS Foundation Trust, South Essex Partnership University NHS Foundation Trust, 2012. *Living well with dementia: a dementia strategy for Essex, Southend and Thurrock*.

Essex Insight, 2013. *Essex Joint Strategic Needs Assessment: Countywide report 2013*. Available at: www.essexinsight.org.uk/get/ShowResourceFile.aspx?ResourceID=299 [Accessed 12 January 2015].

George, J., Adamson, J., Woodford, H., 2011. Joint geriatric and psychiatric wards: a review of the literature. *Age and Ageing* 40, pp.543–548.

Glouberman, S., Zimmerman, B., Commission on the Future of Health Care in Canada, 2002. Discussion Paper No. 9: *Complicated and complex systems: what would successful reform of medicare look like?* Saskatoon: Commission on the Future of Health Care in Canada.

Goldberg, S.E., Bradshaw, L.E., Kearney, F.C., Russell, C., Whittamore, K.H., Foster, P.E.R., Mamza, J., Gladman, J.R.F., Jones, R.G., Lewis, S.A., Porock, D., Harwood, R.H., on behalf of the Medical Crises in Older People Study Group., 2013. Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *BMJ* 347:f4132.

Hawranik, P., Johnston, P., & Deatrich, J., 2008. Therapeutic touch and agitation in individuals with Alzheimer's disease. *Western Journal of Nursing Research*, 30(4), pp.417-434.

Hearn, J., Lawler, J., Dowswell, G., 2003. Qualitative Evaluations, Combined Methods and Key Challenges: General Lessons from the Qualitative Evaluation of Community Intervention in Stroke Rehabilitation. *Evaluation* 9, pp.30–54.

Hussein S., 2011. Volunteers in the formal long-term care workforce in England. *Social Care Workforce Periodical*, 13.

Jurgens, F.J., Clissett, P., Gladman, J.R., Harwood, R.H., 2012. Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. *BMC Geriatrics* 12, 57.

Kail, A., Lumley, T., 2012. *Theory of change: the beginning of making a difference*. London: New Philanthropy Capital.

Kitwood, T., 1997, *Dementia Reconsidered: the person comes first*. Maidenhead: Open University Press.

- Knapp, M., Iemmi, V., Romeo, R., 2013. Dementia care costs and outcomes: a systematic review. *International journal of geriatric psychiatry*, 28, pp.551–561
- Lowson, E., Hanratty, B., Holmes, L., Addington-Hall, J., Grande, G., Payne, S., Seymour, J., 2013. From “conductor” to “second fiddle”: Older adult care recipients’ perspectives on transitions in family caring at hospital admission. *International Journal of Nursing Studies* 50, pp.1197–1205.
- Marchal, B., van Belle, S., van Olmen, J., Hoeree, T., Kegels, G., 2012. Is realist evaluation keeping its promise? A review of published empirical studies in the field of health systems research. *Evaluation* 18, pp.192–212.
- Matthews F.E., Arthur A., Barnes L.E., et al., on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration, 2013. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet*, 382(9902), pp.1405–1412.
- Mead, N., Lester, H., Chew-Graham, C., Gask, L., Bower, P., 2010. Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis, *British Journal of Psychiatry* 196, pp.96–101.
- McNeil, C., Hunter, J., 2014. *The Generation Strain*. London: IPPR.
- Moniz-Cook, E., Vernooij-Dassen, M., Woods, B., Orrell, M., Interdem Network, 2011. Psychosocial interventions in dementia care research: The INTERDEM manifesto. *Aging & Mental Health* 15, pp.283–290.
- Naylor, C., Mundle, C., Weeks, L., Buck, D., 2013. *Volunteering in health and care: securing a sustainable future*. London: The Kings Fund.
- Office for National Statistics (ONS), 2014. *2012-based Subnational Population Projections for England*. Available at: <http://www.ons.gov.uk/ons/rel/snpp/sub-national-population-projections/2012-based-projections/stb-2012-based-snpp.html> [Accessed 12 January 2015]. See also
- Pawson, R. and Tilley, N., 1997. *Realistic Evaluation*. London: Sage.
- Pinquart, M. and Sorensen, S., 2006. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18(4), pp.577–595.
- Sturmberg, J.P., Martin, C.M., 2009. Complexity and health - yesterday’s traditions, tomorrow’s future. *Journal of Evaluation in Clinical Practice* 15, pp.543–548.
- Tanner, C., Brett, B.M., 2014. *“We’ll meet again-don’t know where, don’t know when”: supporting community visiting in Essex Care Homes*. Colchester: University of Essex
- Teasdale S., 2008. *In Good Health. Assessing the impact of volunteering in the NHS*. London: Institute for Volunteering Research.
- Weiss, C.H., 1997. Theory-based evaluation: Past, present, and future. *New directions for evaluation*, 76, pp.41–55.

Weiss, C.H., 1972. *Evaluation Research: Methods of Assessing Program Effectiveness*. Englewood Cliffs, New Jersey: Prentice-Hall.

Wuthnow, R., 1991. *Acts of compassion*. Princeton, New Jersey: Princeton University Press.

Appendix - Dementia care interventions: a review of literature

The literature on interventions to improve dementia care can be categorised according to two dimensions: firstly by the perspective they take on assessing interventions, in other words, the criteria of success; and secondly according to the type of intervention or strategy under consideration. The criteria for success might be:

- cost reduction
- reduction in length of stay
- impact on physical and/or mental health of patients
- patient experience
- impact on carers

As for the type of intervention, this can be:

- specialist care
- particular types of therapy
- psychosocial interventions
- befriending

Interventions may or may not involve volunteers. However, literature on volunteering more generally in hospital settings is covered in section 2.3, so there is less emphasis on it here.

For the purposes of this review, the interest is chiefly in literature which looks at interventions that share features with the Dementia Buddies scheme. So, volunteer befriending schemes are of particular interest, although there is little research in this area.

Interventions aiming to lessen the burden on carers are, similarly relevant, since the Dementia Buddies scheme was set up with this purpose in mind. There is a vast array of literature which might be included, so its selection here depends on it meeting one or more of the following criteria: it is recent; a large-scale or particularly robust study, or a review of literature; or it covers an intervention that is closely comparable with the Buddies Scheme.

Specialist care

Specialist care for older people is one option which demonstrably improves the experience of patients and the satisfaction of carers (Goldberg et al, 2013, George et al., 2011, Lowson

et al, 2010). One example of this claim comes from a randomised control trial, which compared care in a specialist medical and mental health unit with standard care for older people with cognitive impairment admitted to general hospital. It found that in the specialist unit, more family carers were satisfied with care overall and severe dissatisfaction was reduced (Goldberg et al 2013). As for the impact on patients, while their experience improved, there were no marked benefits in their health status or service use. In the light of these findings, the authors reflect that: "Patients' experience and carers' satisfaction might be more appropriate measures of success for frail older people approaching the end of life." (ibid, p2).

Non-pharmacological therapies or treatments

A costs-based review of evidence of dementia care (not confined to hospital care) finds that cognitive stimulation therapy, tailored activity programme and occupational therapy were more cost-effective than usual care (Knapp et al., 2013). The same study reports that coordinated care management and personal budgets held by carers are also cost effective. In addition, it suggests that respite care in day settings and psychosocial interventions for carers may be cost-effective.

Another study, assessing the relative merits of various activities for patients with dementia in nursing homes, finds that the provision of jigsaw puzzles and reminiscing materials improved 'quality of visits' for carers (Crispi and Heitner, 2002).

Psychosocial interventions including befriending

Although interest in psychosocial interventions in dementia care research has been growing, one review suggests that there is a lack of rigorous evaluation and widespread application of such schemes (Moniz-Cooke et al., 2011). One example of psychosocial intervention is befriending, which appears to have a modest effect on depressive symptoms and distress in patients in general (Mead et al, 2010). Since befrienders are usually volunteers, discussion of these two strategies is often interlinked.

A study of a community visitor pilot in Essex (Tanner and Brett, 2014) is particularly relevant in this context (and is consequently referenced at various places in the main report). The

scheme recruited volunteer community visitors (CVs) for care homes with the aim that the CVs befriend members of the care homes and, unlike the Dementia Buddies scheme, also act as critical friends and informal advocates. The evaluation found that the CVs impacted the residents (not all of whom were cognitively impaired) by, for example, providing company and conversation, initiating activities, liaising with friends and relatives. The study also pointed out the challenge of establishing collaborative and mutually understanding relations between volunteers and employees in the home.

The researchers could find few studies specifically of volunteer befriending of people with dementia in a hospital setting but one relevant intervention of this type trained a group of volunteers to provide person-centred support in an acute hospital in Australia (Bateman, 2012). The outcomes were compared with a 'control' hospital where there were no volunteers. In the intervention hospital, staff and volunteers felt there were positive outcomes: nursing staff experienced a reduction in workload pressure and volunteers enjoyed their interactions with patients. But measures to detect differences in outcomes for patients between the intervention and control hospitals failed to demonstrate benefits, these included length of stay, falls, use of anti-psychotic drugs and death rates. On the basis of this and a related study, Dewing and Dijk (2012) speculate that it is unreasonable to expect volunteers to contribute significantly to the complex needs of dementia patients but that "a reduction (or perceived reduction) in workload burden for ward staff might lead to an enhanced focus on person-centred care" (Dewing and Dijk, 2012, p.10).

Interventions targeting dementia caregivers

Pinquart and Sorensen (2006) review 127 intervention studies with dementia caregivers between 1982 and 2005, although almost all of these concern caregiving where the person with dementia is living at home. The review finds that interventions had on average small but significant effects on burden, depression, subjective wellbeing, ability/knowledge and symptoms of care recipients. Psychoeducational interventions that required the active participation of carers were most effective. These cover practical assistance (eg, respite), education, emotional support provision and multicomponent interventions. A recent qualitative study which does explore the experience of family caregivers of people with cognitive impairment admitted to hospital is Clisset et al., (2013). It finds that caregivers try

to stay informed and communicate with staff about the patient and that they either value the support of the hospital staff and services or are highly critical of the care given. As a result, it recommends that nurses should try and foster inclusive relations with carers. This echoes a similar earlier study, which found that enhanced communication between carers and staff can help avoid build-up of a 'cycle of discontent' in which carers become uncertain or suspicious, and consequently engage in 'hyper vigilant monitoring' culminating in challenge, conflict with staff or withdrawal (Jurgens, 2012).