# SettleIN: Using a Manualised Intervention to Facilitate the Adjustment of Older Adults with Dementia Following Placement into Residential Care

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# **UCL Doctorate in Clinical Psychology**

# Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
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### Overview

This thesis focuses on the use of staff training interventions in residential care settings to improve the wellbeing of residents with dementia. The thesis is divided into three parts. Part one is a systemic literature review that examines the effectiveness of staff training programmes in reducing behavioural and psychological symptoms of dementia (BPSD). Twenty-four studies were included in this review. The review also explored whether the theoretical approach and intensity of training altered intervention effectiveness.

Part two is an empirical paper of a pilot randomised control trial designed to evaluate the efficacy of a staff led manualised intervention, SettleIN (Hayward et al., in press). The intervention aimed to facilitate adjustment to residential care for people with dementia (PWD). The paper focused on the effect of the intervention on residents' psychological wellbeing, quality of life and overall adjustment. The feasibility and acceptability of SettleIN were also evaluated. Data was collected at baseline, week zero, and at post-intervention, week seven. This was a joint project completed with Judy Murrill, with Murrill (2018) focusing on staff outcomes.

Part three is a critical appraisal, which reflects on the barriers and dilemmas that were present during the development, implementation and evaluation of SettleIN. The appraisal utilises the existing guidelines around developing and evaluating complex interventions (Craig et al., 2008) to consider the feasibility issues that would need to be resolved before attempting a larger scale RCT.

## **Impact Statement**

The main beneficiaries of this research were the residents involved. The work highlighted the potential positive effects that psychosocial, staff led programmes can have on people with dementia (PWD). The qualitative data obtained in the empirical paper indicated that taking part in the SettleIN trial was helpful, comforting and positive for residents. This not only has implications for the residents in the recruited care homes but following publication could lead to positive changes in how other care homes support residents during the adjustment period.

Following recent government recommendations to increase the use of staff training programmes, the thesis also has important implications for care home organisations. The findings from the literature review indicated that not all training programmes were effective in reducing resident BPSD. This will hopefully encourage organisations to carefully consider the training programmes delivered, ensuring that the interventions chosen have support from clinical trials.

The work has also demonstrated that organisational barriers and task focused care can prevent lasting positive changes to care practice. The results will be disseminated to the care homes involved in the trial and, through scholarly journals, will be available to care home organisations on a larger scale. It is hoped that this will lead to changes in the wider care home culture, ensuring that organisations give their staff the time and the training to engage in person centred care.

The results of this thesis are also beneficial within academia. The work highlighted the difficulties of using existing validated outcome measures with PWD. Both the literature review and empirical paper demonstrated that existing measures are challenging for individuals with severe dementia to complete, resulting in a

reliance on by-proxy measures. It is hoped that reporting such challenges will have an impact on the methodology and choice of outcome measures used in future trials, ensuring that the perspectives and experiences of PWD are not missed.

More broadly, the results of this study could contribute to the development of best practice guidelines for new residents' first few weeks in residential care. There are currently no guidelines in place and the existing adjustment support in care homes was found to be minimal. The high levels of resident depression found, following relocation, highlight the need for such guidelines, to improve care home practice and ultimately the wellbeing of residents.

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**Empirical Paper** 

Figure 1:

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# **Part 1: Literature Review**

The Effectiveness of Staff Training Interventions in Reducing

Behavioural and Psychological Symptoms of Dementia: An Updated Systematic

Review

#### **Abstract**

**Background:** Behavioural and psychological symptoms of dementia (BPSD) are experienced by a significant proportion of individuals living in residential care, affecting the well-being of residents and their caregivers. This review aimed to update a previous review (Spector, Orrell & Goyder, 2013), evaluating the effectiveness of staff training interventions in reducing BPSD. The review also aimed to explore whether the theoretical approach and intensity of training altered intervention effectiveness.

**Method:** PubMed, PsycINFO, EMBASE Medline and CINAHL databases were searched for studies published between February 2010 and August 2017. From the 148 studies found, 11 met the inclusion criteria and were added to the 13 studies from the previous review. Twenty-four studies were therefore included; the quality was evaluated using the modified Jadad criteria (Jadad et al., 1996).

Results: The quality of studies was variable. Overall, more recent studies were deemed to be of higher quality than the studies included in the previous review. Thirteen studies found a positive effect of staff training on at least one resident outcome measure. No evidence was found to suggest that the effectiveness of staff training differed according to the theoretical approach or intensity of training. Interventions involving staff supervision were most likely to be effective.

Conclusion: This review found evidence to suggest that staff training programmes can successfully reduce resident BPSD, however this effect was not consistent across studies. Since the previous review, though, there is now more support for the use of staff training interventions in reducing resident depression. The impact of organisational barriers on staff training effectiveness is discussed.

### Introduction

It is currently estimated that 850,000 individuals are living with dementia in the UK (Prince et al., 2014). The disease not only impacts upon individuals and their families personally, but also has a significant impact on the UK economically. There are suggestions that by 2020 dementia will cost the UK £30 billion (Lewis, Schaffer, Sussex, O'Neill & Cockcroft, 2014); a figure that is predicted to rise further as the prevalence of the disorder increases.

Dementia is defined as a collection of 'progressive neurological disorders that impair cognition in multiple domains and interfere with daily function' (McConnell & Karel, 2016, p. 245). Although cognitive deterioration is considered the focal feature of dementia (Whear et al., 2014), behavioural and psychological symptoms of dementia (BPSD) are gathering increasing attention in psychological research (Finkel, 2001).

# Behavioural and Psychological Symptoms of Dementia

Of the estimated 250,000 people with dementia living in care homes in the UK (Prince et al., 2014), approximately 90% experience BPSD (Thraves, 2016). BPSD can include depression, anxiety, the experience of delusions or hallucinations, agitated or aggressive behaviours and apathy (Selbaek, Engedal & Bergh, 2013). People experiencing BPSD often have poorer outcomes (Russ, Batty & Starr, 2012); with symptoms commonly leading to high levels of distress (Cerejeira, Lagarto & Mukaetova-Ladinska, 2012), increased mortality rates (Russ et al., 2012), carer burden (Rojas, Bartoloni, Dillon & Serrano, 2011) and earlier residential care admission (Herrmann & Black, 2000).

Historically, antipsychotic medication has been used as the most common treatment for BPSD (Lee et al., 2004), particularly in care home settings (Barnes et al., 2012). Extensive research, though, has indicated that the use of atypical antipsychotics in dementia is associated with adverse side effects (Wang et al., 2015), increased mortality rates (Pratt, Roughead, Ryan & Salter, 2010) and limited effectiveness (Schneider et al., 2006). Non-pharmacological interventions have therefore been recommended as the principle treatment for BPSD (Wang et al., 2015); perhaps contributing to the significant decline, in antipsychotic prescriptions, from 2005 to 2015, for people with dementia (Donegan et al., 2017). Moving away from pharmacological approaches, however, means that effective non-pharmacological alternatives for managing neuropsychiatric symptoms are needed (Ballard et al., 2016).

# **Staff Training**

Staff training has been offered as a solution (Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield & Moyle, 2010). Staff training interventions aim to create positive changes in caregivers' behaviour, which in turn lead to improvements in the wellbeing of residents (Kuske et al., 2007). Staff who are not trained to identify the effects of dementia on behaviour, cognition and communication, may fail to meet residents' needs; potentially contributing towards BPSD (McConnell & Karel, 2016). It has been argued that staff should therefore be trained to recognise the various elements that affect BPSD so that they can make considerations for this in their daily practice (McConnell & Karel, 2016). Interventions use various methods to achieve this depending on the theoretical model they are based upon.

In recent years, an increasing amount of research has focused on training for care home staff (Kuske et al., 2007). Alongside this, two government reports have been issued setting out planned changes for dementia research and care; the Prime-Minister's challenge on dementia (Department of Health, 2012) and the Prime-Minister's challenge on dementia 2020 (Department of Health, 2015). Both reports emphasise the importance of training programmes for those supporting individuals with dementia. With evidence that government dementia policy can effect health care practice (Donegan et al., 2017), these reports may result in an increase in the use of training programmes for care home staff; making the need for a review of the evidence base ever more apparent.

#### **Previous Literature Reviews**

Previous literature reviews have often focused on non-pharmacological treatments generally rather than staff training programmes specifically (Spector, Orrell & Goyder, 2013). Reviews that have included staff training interventions have reported mixed findings. Staff training programmes have been shown to reduce levels of resident agitation for up to six months post-intervention (Livingston et al., 2014). Other reviews, however, have suggested that staff training programmes are no more effective than care as usual in reducing agitation and aggression in residents (Jutkowitz et al., 2016) and that a significant majority of the training manuals used in care homes are not evidence based (Fossey et al., 2014). The quality of the research methodology in care homes has often been considered weak (Kuske et al., 2007; a factor that may have contributed to inconclusive results, leading to recommendations that results should be interpreted with caution (Kuske et al., 2007; Richter, Meyer, Möhler & Köpk, 2012).

A recent review used qualitative data from care home staff to evaluate the factors that contribute to the success of training programmes (Rapaport, Livingston, Murray, Mulla & Cooper, 2017). The authors concluded that programmes that included supervision were seen as more effective by staff members; a finding supported by other literature (Livingston et al., 2014). The review also indicated, however, that the positive effects of training were not sustained long term (Rapaport et al., 2017). Additionally, higher intensity training programmes were deemed to be problematic for staff to maintain in a care home setting. This research leads to further questions about the optimum duration and intensity of training, as well as the potential importance of supervisory support in evidence based training programmes.

Spector et al., (2013) considered these intervention characteristics in a review of staff training interventions. Unlike previous reviews, psychological outcomes such as depression and anxiety were also considered. This enabled a complete review of the effect of staff training programmes in reducing behavioural and psychological symptoms of dementia (Spector et al., 2013).

No conclusive evidence was found regarding the effectiveness of staff training, as many of the studies reviewed were rated as poor quality (Spector et al., 2013). When positive effects were observed, however, these were maintained at later follow-up points. The review found no evidence that a particular theoretical model was superior or that a set duration was most effective; training programmes with a supervisory component, however, were recommended.

#### **Current Literature Review**

Given the described economic and personal costs of BPSD, as well as the need for evidence based non-pharmacological interventions, an updated review was

required to investigate changes in evidence since the previous review. This review aimed to expand upon Spector et al.'s (2013) systematic review by examining the literature published from February 2010, when the previous search ended.

There has been a growth of research in this area since the previous review (McConnell & Karel, 2016). The main aim was, therefore, to provide an update on the effectiveness of staff training programmes in reducing BPSD; advancing the current literature by examining more recent research. The review also aimed to compare the effectiveness of types of training programmes, to establish whether certain approaches should be favoured. It was also hoped that the quality of studies would have improved, as this has been the frequent recommendation of research guidelines (Moher et al., 2010; Campbell, Elbourne & Altman, 2004).

# **Literature Review Questions**

- 1) Do staff training programmes significantly reduce BPSD in care home residents with dementia?
- 2) Does the effectiveness of staff training programmes differ depending on the theoretical approach of the programme?
- 3) Does the effectiveness of staff training programmes vary depending on the programme intensity?

#### Methods

This review followed the recommendations of the York Centre for Reviews and Dissemination (University of York, 2009) on conducting systematic reviews in a health care setting. Unlike Spector et al. (2013), this review only included

randomised studies as these are considered to be the best form of evidence when evaluating intervention effectiveness (NICE, 2006).

### **Inclusion Criteria:**

- Randomised-control trials and multiple group comparison designs
- Published between February 2010 to August 2017
- Professional staff training programmes aimed at reducing behavioural and/or psychological symptoms of dementia for residents in a nursing/ residential care home setting
- Studies with resident psychological or behavioural outcomes
- Studies published in English in peer reviewed journals

### **Exclusion Criteria:**

- Training programmes for family or non-professional caregivers
- Studies not based in residential/ nursing home settings
- Studies with outcome measures that are purely staff focused
- Studies without psychological outcome measures
- Qualitative research, case studies or thesis dissertations

# **Search Strategy**

A systematic literature search was conducted using PubMed, PsycINFO, EMBASE Medline and CINAHL databases in August 2017. The search was restricted to research published after January 2010, the date at which the search from the previous review (Spector et al., 2013) ended. Identical keywords were used in each search, in order to find publications of staff training interventions ('staff

training', 'staff education'), delivered to care staff ('nursing staff', 'nursing', 'care', 'caregiver/s', 'staff', 'care assistant/s', 'carer/s') within a care home setting ('nursing home', 'care home', 'assisted living residence', 'residential care institution', 'long-term care'), with individuals with a dementia diagnosis ('dementia', 'Alzheimer's disease'), investigating the impact on behavioural and psychological symptoms of dementia ('behavioural problems', 'psychological symptoms', 'psychiatric symptoms', 'agitation', 'aggression', 'depression', 'anxiety', 'challenging behaviour'). Alternative spellings of the keywords were also included in the search.

The titles and abstracts of all studies were screened according to the inclusion and exclusion criteria; full paper reviews were conducted with articles that seemed relevant following this initial screening. A reference list search was conducted with publications that met the inclusion criteria, in order to identify additional studies. The studies that met the inclusion criteria were then added to the list of randomised studies from the previous review (Spector et al., 2013); all non-randomised studies from the previous review were discarded.

# **Assessing the Quality of Studies**

Jadad et al.'s (1996) criteria were used to assess the quality of the studies examined (see Appendix A). The Jadad criteria examine the randomisation method used, the use of blinding and the description of attrition; providing studies with a score between 0 and 5. A modified version of the Jadad scale was used in this review, as one item was removed from the criteria. The deleted item questioned whether the studies examined were double-blind, which is not applicable to psychological research. The maximum score was therefore reduced to four, with studies deemed to be the highest quality achieving four out of four.

The CONSORT guidelines (Campbell, Elbourne and Altman, 2004) were also consulted to assess the quality of control trials using cluster randomisation. Cluster randomised control trials (CRCTs) are randomised by units, in this case care homes, rather than by individuals. The CONSORT guidelines provide a checklist as to what additional factors should be included in CRCT publications, for example it recommends that studies state how clustering effects were accounted for in both the planning of the study and the analysis of results. The CONSORT guidelines contributed to the qualitative evaluation of the strengths and weaknesses of all of the studies in this review; this is summarised in Table 1.

### **Data Extraction**

The information extracted from studies included: details of the study design, training information (duration, total number of hours and use of supervision in training programmes), number of resident participants, outcome measures and results. Authors of the publications examined were contacted, where possible, if data was missing or if additional information was needed.

# **Data Synthesis**

The publications were categorised by the approach of the training programme utilised. Six categories were used, including; behavioural orientated approaches with person-environmental fit, communication approaches, person-centred approaches, emotion-orientated approaches, practical BPSD-management approaches and other approaches.

In order to compare the intensity of training across studies, the total number of hours of training was also categorised into low, medium and high intensity. These

classifications were calculated from the median length of training for all of the studies included in this review. Ten hours and under was considered to be low intensity, between 11 and 19 hours was considered to be medium intensity and 20 hours and over was categorised as high intensity.

#### **Results**

### **Results Overview**

The database search yielded 147 studies, 137 of which were excluded based on the criteria described above. An additional study was identified through reference list searching. These 11 studies were then combined with 13 studies from the previous review (Spector et al., 2013) that had met the updated inclusion criteria. In total 24 studies were included in the final review. Please see figure 1 for a summary of the search and study selection process.

# **Study Characteristics**

Of the 24 studies examined, 22 employed a cluster randomised control (CRCT) design. Of the two remaining studies, one utilised a randomised two group comparison design and the other was a randomised controlled trial. See Table 1 for a summary of the final studies reviewed.

The 24 studies were divided into groups based on the theoretical approach of the staff training intervention conducted.

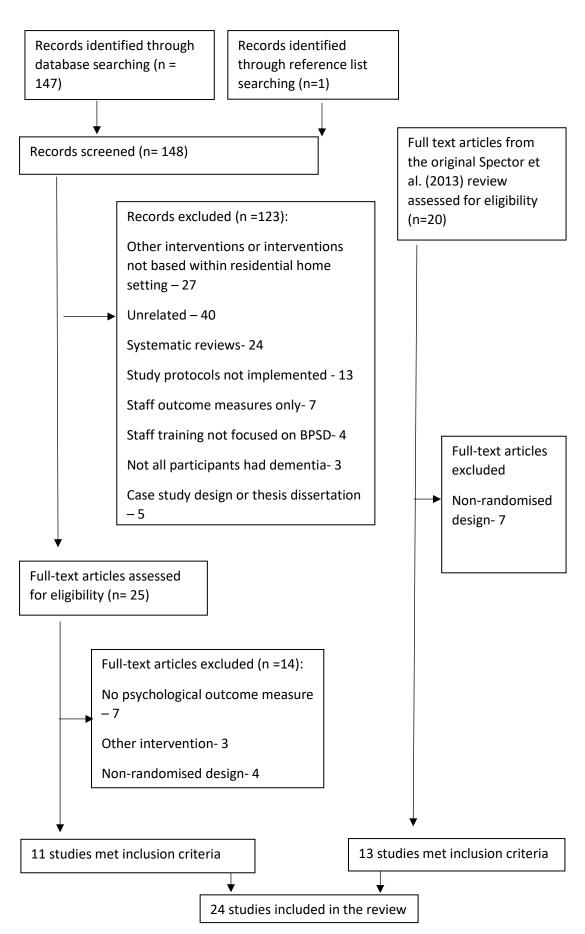


Figure 1: Flow chart of study selection

Behavioural orientated approaches with person-environmental fit. Five of the training programmes reviewed were based on this approach (Davison et al., 2007; McCabe et al., 2015; Teri, Huda, Gibbons, Young & van Leynseele, 2005; Visser et al., 2008; Wenborn et al., 2013). All of these programmes are centred on behavioural principles, whilst also valuing the differing needs of individuals in response to environmental stresses. The majority of these programmes, in line with social learning theory (Bandura, 1978), taught staff to consider the antecedents and consequences of behaviour in order to detect reinforcing and maintaining factors (Davison et al., 2007; McCabe et al. 2015; Teri et al., 2005; Visser et al., 2008). One behavioural intervention focused on occupational therapy principles, training staff to engage residents in activities that were designed to improve physical and mental well-being (Wenborn et al., 2013).

Communication approaches. Three training programmes used communication approaches, in an attempt to reduce BPSD (Magai, Cohen & Gomberg, 2002; McCallion, Toseland, Lacey & Banks, 1999; Sprangers, Dijkstra & Romijn-Luijten, 2015). Such programmes taught practical communication strategies, to facilitate more positive interactions and enable residents to express their wants, needs and emotions. One training programme focused on non-verbal communication skills only (Magai et al., 2002), one training programme concentrated on verbal communication (Sprangers et al., 2015) and one training programme explored both means of communication (McCallion et al., 1999).

**Person-centred approach.** Four training programmes utilised this approach (Chenoweth et al., 2009; Chenoweth et al., 2014; Rokstad et al., 2013; Van de Ven et al., 2013). Person-centred care prioritises the perspective of the individual, encourages relationships, engages with the person and focuses on strengths-based

care, rejecting task-focused approaches (Waters & Buchanan, 2017). Chenoweth et al. (2014) focused on a more general person-centred care training model, comparing this to the effects of a person-centred physical environment. The remaining three person-centred training programmes used a dementia care mapping model; an approach in which detailed observations of the individual with dementia are conducted, in order to guide staff and person-centred care practices (Chenoweth et al., 2009; Rokstad et al., 2013; Van de Ven et al., 2013).

Two of the studies using a dementia care mapping model compared this with other person-centred approaches. Chenoweth et al. (2009) compared dementia care mapping with general person-centred care training and care as usual. Rokstad et al. (2013) compared dementia care mapping to general dementia education and the VIPS practice model, a person-centred training programme that focuses on staff consultations based on the following principles: valuing individuals with dementia (V), providing individualised care (I), understanding residents' perspectives (P) and creating a social environment within residential living (S).

Emotion-orientated approach. This model was employed by two of the training programmes reviewed (Finnema et al., 2005; Schrijnemaekers, van Rossum, Candel & Frederiks, 2002). This approach utilises validation therapy principles (Feil, 1992) to teach staff how to validate and acknowledge the emotional experiences of the resident.

**Practical BPSD-management.** Two of the studies utilised this approach (Deudon et al., 2009; Leone et al., 2013). Practical BPSD management utilises tools such as training cards, in order to provide practical advice and recommendations of ways to respond to specific behaviours displayed by residents.

Other approaches. Most frequently, training programmes were categorised as 'other' suggesting that the approach of the training did not fit into one of the other named categories. Eight training programmes were included in this group (Fossey et al., 2006; Lichtwarck et al., 2018; McCurry, LaFazia, Pike, Logsdon & Teri, 2012; Pieper et al., 2016; Proctor et al., 1999; Testad, Aasland, & Aarsland, 2005; Testad, Ballard, Brønnick & Aarsland, 2010; Testad et al., 2016).

These approaches included: education and skills based interventions focused on specific problem areas; restraint reduction (Testad et al., 2005, Testad et al., 2010, Testad et al., 2016) and sleep disturbance (McCurry et al., 2012); a goal planning approach (Proctor et al., 1999), which focused on training staff to conduct detailed observations in order to set suitable goals for residents based on their strengths and difficulties; an interdisciplinary conference approach, involving case conferences based on CBT principles (Lichtwarck et al., 2018); a systemic consultation approach, integrating various methods including behavioural, communication and skills based approaches (Fossey et al., 2006) and a stepwise multidisciplinary intervention, a protocol based approach involving a detailed assessment of physical and emotional needs (Pieper et al., 2016).

# The Quality of Studies Reviewed

Table 1 provides details on the quality rating for all studies included in the review. Six studies reviewed received the highest quality rating of 4/4 (Chenoweth et al., 2009; Chenoweth et al., 2014; Fossey et al., 2006; Lichtwarck et al., 2018; Pieper et al., 2016; Rokstad et al., 2013). Of the six highest quality studies, four were published post 2010. These studies all described an appropriate method of

randomisation, used single blind assessors and provided details regarding participant withdrawals and drop-outs.

Four studies were deemed to be of low quality, scoring 1/4 on the modified Jadad scale (Jadad et al., 1996) (Davison et al., 2007; McCallion et al., 1999; Testad et al., 2010; Visser et al., 2008). All of these studies were obtained from the previous review. Low quality studies were deemed to have not successfully followed CONSORT guidelines.

Six studies were rated 3/4 on the Jadad scale (Jadad et al., 1996), suggesting that they were medium quality (McCabe et al., 2015; McCurry et al., 2012; Proctor et al., 1999; Testad et al., 2005; Van de Ven et al., 2013; Wenborn et al., 2013). The eight remaining studies received a rating of 2/4.

The studies within the person-centred approaches group achieved, on average, the highest quality rating (M=3.75); the communication approaches group received the lowest mean quality rating (M= 1.67).

# The Effect of Staff Training Programmes on Resident BPSD

Of the 24 training programmes reviewed, 13 had a significant positive effect on at least one resident BPSD outcome (Chenoweth et al., 2009; Chenoweth et al., 2014; Deudon et al., 2009; Finnema et al., 2005; Leone et al., 2013; Lichtwarck et al., 2018; McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016; Proctor et al., 1999; Teri et al., 2005; Testad et al., 2010; Rokstad et al., 2013). Four of these studies found that, when compared to the control group, staff training had a significant positive impact on all of the resident outcomes measured. In contrast, 10

out of the 24 studies found that staff training had no significant positive impact on any of the symptoms measured.

This review examined the impact of staff training on a wide range of behavioural and psychological symptoms, with many of the studies incorporating multiple outcome measures. These outcomes are examined separately below.

Behavioural symptoms of dementia. Of the 22 studies that included behavioural outcomes, 10 found a significant positive effect of staff training (Chenoweth et al., 2009; Chenoweth et al., 2014; Deudon et al., 2009; Leone et al., 2013; Lichtwarck et al., 2018; McCallion et al., 1999; Pieper et al., 2016; Rokstad et al., 2013; Teri et al., 2005; Testad et al., 2010).

Table 1
Summary of the studies investigating the effectiveness of staff training interventions on BPSD

Authors	Design	N and setting	Description of intervention	Resident outcome measures and points of data collection	Results	Jadad quality ratings	Qualitative evaluation of study quality
	Behavioural o	orientated approach	h with person-environmental fit				
Teri et al., (2005)	CRCT	Residents 31 4 assisted living residences, USA	STAR training vs. Usual general information training Single blind Intervention duration: 8 weeks Total training hours: 10 Low intensity Supervision: 2 hours	RMBPC, GDS, CAS, Baseline and 8 week follow-up	Sig. greater reductions in anxiety (CAS) (NR, p=.002), depression (GDS) (NR, p<.001) and behavioural problems (RMBPC: NR, p<.001; NPI: NR, p=.031; ABID: NR, p< .001) in intervention vs control group.	2/4: Low-medium quality	Positive: Adjustments made to analysis to account for clustering effects, blind assessors were used Negative: Power analysis was not described, randomisation method not described
Davison et al., (2007)	CRCT	Residents 113 6 residential care homes, Australia	Training and peer support vs. Training only vs. Waitlist condition Non blind Intervention duration: 8 weeks Total training hours: 10 Low intensity Supervision: None reported	CMAI  Baseline, 8  week and 6  months follow- up	No sig. difference between groups in the change in agitation (CMAI) scores (F=3.20, p=.077).	1/4: Low quality	<u>Positive:</u> 6 month follow-up, residents assessed by two staff-raters, high inter-rater reliability for CMAI <u>Negative:</u> Randomisation not described, power analysis not described, non-blind, no adjustments for clustering effects, no intention-to-treat analysis and attrition not described.

Visser et al., (2008)	CRCT	Residents 76 3 residential care homes, Australia	Training and peer support vs. Training only vs. Waitlist condition Non-blind Intervention duration: 8 weeks Total training hours: 10 Low intensity Supervision: None reported	CMAI, ADRQL, restraint  Baseline, 8 weeks, 3 and 6 months follow- up	No sig. difference in aggression (CMAI) or quality of life (ADRQL) scores between groups at post-intervention or follow- up (NR).	1/4: Low quality	Positive: 6 month follow up, inter-rater reliability described Negative: Randomisation method was not described, power analysis was not described, attrition was not described, no intention-to-treat analysis, no adjustments were made to account for clustering effects
Wenborn et al., (2013)	CRCT	Residents 210 16 care homes, UK	Occupational therapy training programme vs. Care as usual Single blind Intervention duration: 16 weeks Total training hours: 10 Low intensity Supervision: time not specified	QOL-AD, CAPE-BRS, CBS, CSDD, RAID  Baseline, 20 and 28 weeks follow-up	No sig. difference between conditions in functional ability (CAPE-BRS) (NR, p=.63), challenging behaviour (CBS) (NR, p=.75), depression (CSDD) (NR, p=.89) or anxiety (RAID) (NR, p=.59) at follow-up. Staff rated quality of life (QOL-AD) was sig. lower at follow-up in training group compared to control (NR, p=.03).	3/4= Medium quality	Positive: Groups were matched at baseline, data analysis and power calculations adjusted for cluster effects, blind assessors used, intention-to-treat analysis used Negative: Reliability and validity were not demonstrated for all measures, randomisation method not described

McCabe et al., (2015)	CRCT	Residents 187  16 residential care homes, Australia	staff training and support vs. Staff support only vs. Staff training only vs. Care as usual Single blind Intervention duration: 12 weeks Total training hours: 2 Low intensity Supervision: 12 hours for the training and support group and support only group.	CMAI  Baseline, 3  months and 6  months follow  up	No sig. difference between groups in the change in agitation scores (CMAI) (NR).	3/4: Medium quality	Positive: 6 months follow up, four armed trial, randomisation described, single blind assessors, interrater reliability of CMAI measures  Negative: Groups not matched at baseline, power calculation and data analysis were not adjusted for cluster effects, no intention-to -treat analysis
	Communication	approaches					
McCallion et al., (1999)	CRCT	Residents 105 2 nursing homes, USA	Nursing assistant communication skills programme vs. Waitlist condition Single blind Intervention duration: 2 weeks Total training hours: 7.8 Low intensity Supervision: 4 hours	CSDD, CMAI, medication, restraint  Baseline, 3 and 6 months	Sig. group by time interaction favouring intervention group for behavioural (F=18.64, p<.001) and ideational (F=5.60, p<.05) disturbance (CSDD) and verbal aggression (F=14.23, p<.001) (CMAI).	1/4: Low quality	<u>Positive:</u> 6 month follow-up, blind assessors used <u>Negative:</u> Analysis and study design were not adjusted for clustering effects, power analysis not described, attrition not described, no intention-to-treat analysis

Magai et al., (2002)	CRCT	Residents 91 3 nursing homes, USA	Non-verbal sensitivity training vs. General dementia education training vs. Waitlist condition Single blind Intervention duration: 2 weeks Total training hours: 10 Low intensity Supervision: None reported	BEHAVE-AD, CMAI, CSDD, MAX Baseline, 3, 6, 9 and 12 weeks	No sig. difference between groups in behaviour problems (BEHAVE-AD: F= 1.55, p=.17; CMAI: NR) or depression scores (CSDD) (F= 1.6, p=.14) at follow-ups.	2/4: Low- medium quality	Positive: Three armed trial, multiple follow-ups, trainer and assessors were blind to study hypotheses, inter-rater reliability demonstrated on outcome measures rated by staff Negative: Design and analysis were not adjusted for clustering effects, method of randomisation not described, no intention-to-treat analysis
Sprangers et al., (2015)	Randomised two group comparison design	Residents 26  1 nursing home, the Netherlands	Communication skills training vs. Care as usual Non-blind Intervention duration: 8 weeks Total training hours: 0.5 (average) Low intensity Supervision: None reported	CMAI, NPI-Q Measures translated into Dutch  Baseline and 8 weeks	No sig. difference in agitation (CMAI) (NR) or neuropsychiatric symptoms (NPI-Q) (F=2.88, p=.10) between groups	2/4: Low-medium quality	Positive: Interrater reliability on observational measures, reliability and validity of translated measures demonstrated Negative: Power analysis not described, small sample size, no single blind assessors, would benefit from longer term follow up, randomisation not described

# Person-centred approaches

Chenoweth et al., (2009)	CRCT	Residents 289 15 care homes, Australia	Person-centred care training vs. DCM vs. Care as usual Single blind Intervention duration: 4 months Total training hours: 18 Medium intensity Supervision: duration not specified	CMAI, NPI, QUALID, QUIS, TESS- NH, Baseline, 4 months and 8 months follow- up	Sig. lower problem behaviours (CMAI) in PCC (NR, p=.01) and DCM (NR, p=.04) vs control at follow-up. No sig. difference in psychiatric symptoms (NPI) (NR, p=.30) or quality of life (QUALID) (NR, p=.33) between groups.	4/4: High quality	Positive: 8 month follow-up, analysis and study design were adjusted for clustering effects, intention-to-treat analysis used Negative: Groups were not matched at baseline, however this was considered in the analysis
Rokstad et al., (2013)	CRCT	Residents 446  15 nursing homes, Norway	vs. VPM vs. Dementia education only Single blind Intervention duration: 10 months Total training hours: intervention groups: 29.5 control group: 2.5 High intensity Supervision: DCM: 6 hours VPM: 20 hours	BARS, NPI-Q, CSDD, QUALID Baseline and 10 months	Non sig. difference in agitation (BARS) compared to control (DCM: NR, p= 0.19; VPM: NR, p= .42). Sig. reduction in agitation (NPI-Q subscore) (DCM: NR, p=.04; VPM: NR, p=.02), and overall neuro-psychiatric symptoms (NPI-Q) (DCM: NR, p=.01; VPM: NR, p=.01) vs. control. Sig reduction in depression (CSDD) for VPM vs control (NR, p=.02). Sig increase in quality of life (QUALID) for DCM vs. control (NR, p=.02).	4/4: High quality	Positive: Attrition described, single blind assessors, randomisation described, data analysis adjusted for cluster effects, large sample size  Negative: No intention to treat analysis, groups not matched at baseline, power analysis not adjusted for cluster effects

Van de Ven et al., (2013)	CRCT	Residents 192 11 care homes, the Netherlands	DCM training vs. Care as usual Non-blind Intervention duration: 4 months Total training Hours: 56 High intensity Supervision: None reported	CMAI, NPI-NH, Qualidem, EuroQol 5D  Baseline, 4 -6 months and 8-12 months follow up	Non sig. difference in agitation (CMAI) (NR, p= .34) or quality of life (Qualidem: NR, p= .995; EuroQol 5D: NR, p= .09) between groups at follow-up. Sig. group by time interaction effect for neuropsychiatric symptoms (NPI-NH) favouring the control group (NR, p= .02).	3/4: Medium quality	Positive: Randomisation described, CMAI validated for Dutch population, 12 months follow up, intention to treat analysis used, groups matched at baseline Negative: All measures were by proxy, follow up times not standardised, no single blind assessors
Chenoweth et al., (2014)	CRCT	Residents 601  38 Residential care homes, Australia	Person centred care training (PCC) vs. Person centred environment (PCE) vs. Person centred care and person centred environment (PCC-PCE) vs. Care as usual Single blind Intervention duration: 6 months Total training hours: 32 High intensity Supervision: 2-16 hours	DEMQoL, CMAI, ERIC, CSDD, QUIS Baseline, 6 months and 8 months follow- up	Non sig. difference in quality of life (DEMQoL) (NR, p=.23), emotional responses (ERIC) (NR, p=.07) or depression ratings (CSDD) (NR) between groups. Sig. group by time interaction effect for agitation (CMAI) scores in favour of the PCC and PCE only groups (NR, p=.01). Sig. group by time interaction effect for care interaction quality (QUIS) in favour of the combined PCC-PCE group (NR, p=.007).	4/4: High quality	Positive: 8 month follow up, power calculation and data analysis adjusted for cluster effect, single blind assessors used, intention to treat analysis used, large sample size  Negative: Care homes varied in implementation of intervention, psychometric properties of measures not described

Emotion-orientated app	proaches
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Emotion-offentated approaches								
Schrijnemae kers et al., (2002)	CRCT	Residents 151 16 homes for aged, Netherlands	Emotion orientated care training vs. Care as usual Non-blind Intervention duration: 3 months Total training hours: 52.5 High intensity Supervision: 10.5 hours	DBRSP, GRGS, CMAI, ADL Baseline, 3, 6 and 12 month follow-up	No sig. difference in challenging behaviours (DBRSP and GRGS) or agitation (CMAI) scores between groups (NR).	2/4: Low-medium quality	Positive: 12 month follow- up, intention-to-treat analysis used, data analysis adjusted for cluster effects, attrition described Negative: Blind assessors were not used, randomisation method not described	
Finnema et al., (2005)	CRCT	Residents 146 14 nursing homes, Netherlands	Emotion orientated care training vs. Care as usual Non-blind Intervention duration: 7 months Total training hours: 16 Medium intensity Supervision: None reported	ASEP, CSDD, CMAI Baseline and 7 months	Sig. between group differences in emotional adaption (maintaining emotional balance, CSDD, BIP and CMAI: F=3.3; p=.04; maintaining a positive self-image, PGCMS and BIP: F=4.63; p=.04) in favour of the intervention group but only among people with mild-moderate dementia. No significant difference between groups regarding social (F=0.03; p=.86) adaption.	2/4: Low-medium quality	Positive: Inter-rater reliability demonstrated, data analysis adjusted for cluster effects, satisfactory handling of attrition Negative: Method of randomisation not described, no blinding of assessors, power analysis not adjusted for clustering effects, no intention-to-treat analysis was used	

# **Practical BPSD management approaches**

Deudon et al., (2009)	CRCT	Residents 306  16 nursing homes, France	BPSD staff training vs. Care as usual Single blind Intervention duration: 18 weeks Total training hours: 25.5 High intensity Supervision: 24 hours	CMAI, NPI, OS Baseline, 8 and 12 weeks follow-up	Sig. difference between groups in agitation (CMAI) (NR, p=.001), observed agitation (OS) (NR, p<.001) and hyperactivity (NPI) (NR, p=.032) in favour of intervention. No sig. difference between groups in psychotic symptoms (NPI) (NR, p=.119).	2/4: Low-medium quality	Positive: 12 week follow-up post intervention, blind assessors, observational measure used, attrition described Negative: Randomisation method not described, analysis was not adjusted for cluster effects, no inter-rater reliability on observational measure, no intention-to-treat analysis
Leone et al., (2013)	CRCT	Residents 230 16 nursing homes, France	BPSD staff training vs. Care as usual Single blind Intervention duration: 1 month Total training hours: 18 Medium intensity Supervision: None reported	Katz ADL scale, NPI-NH, AI-C, GOS and IOS.  Baseline, 4 weeks and 3 months follow-up	Affective (NR, p< .01) and psychotic (NR, p< .01) scores (NPI-NH) increased in intervention group at 4 weeks only. Improved functional ability (Katz ADL: toileting, transferring) (NR, p< .05) and emotional blunting (AI-C) (NR, p< .01) in intervention group. No between-group comparisons or exact p values reported.	2/4: Low-medium quality	Positive: 17 week follow up, blind assessors used, observational measures used, intention to treat analysis Negative: Power calculations and randomisation not described, groups not matched at baseline although this was adjusted for in the analysis, validity and reliability of measures were not demonstrated, attrition not fully explained

# Other approaches

Proctor et al., (1999)	CRCT	Residents 120  12 residential care homes, UK	Goal planning training vs. Care as usual Non-blind Intervention duration: 6 months Total training hours: 19 Medium intensity Supervision: 24 visits	AGECAT, Chrichton Scale, Barthel Index Baseline and 6 months	Sig. greater reductions in depression scores (AGECAT) in the intervention group compared to control (NR, p= .04). No sig. difference in behavioural problems (Chrichton) (NR, p= .556) or activities of daily living (Barthel) (NR, p= .292) between conditions at follow-up. Sig. fewer GP visits to homes in intervention condition compared to control (NR, p= .027).	3/4: Medium quality	Positive: Randomisation method described, data analysis adjusted for clustering effects, attrition handled appropriately Negative: Power analysis did not adjust for clustering effects, no longer term follow-up, no intention-to-treat analysis reported, assessors were not blind
Testad et al., (2005)	CRCT	Residents 151 4 nursing homes, Norway	Staff training vs. Care as usual Single blind Intervention duration: 7 months Total training hours: 12 Medium intensity Supervision: none	BARS  Baseline and 7 months	No sig. between group differences in agitation scores (BARS) at follow-up (Mann—Whitney $U$ = 8,068,500; p= .052). The number of restraints used was significantly lower in the intervention group compared to control (Mann—Whitney $U$ = 1,778,000; p= .017).	3/4: Medium quality	Positive: Blind assessors used, attrition described Negative: Randomisation method not described, power calculation and data analysis were not adjusted for cluster effects, no intention-to-treat analysis, no longer term follow-up

Fossey et al., (2006)	CRCT	Residents 306 12 nursing homes, UK	Staff training and support intervention vs. Care as usual Single blind Intervention duration: 10 months Total training hours: approx. 25 High intensity Supervision: None	CMAI, prescriptions of neuroleptics  Baseline and 12 months follow-up	No sig. difference in agitated behaviour (CMAI) between groups (NR, p= .94). Sig. lower proportion of participants taking neuroleptics in the intervention group compared to control (NR, p= .045).	4/4: High quality	Positive: Blind assessors used, randomisation method described, study design and data analysis adjusted to account for clustering effects, intention-to-treat analysis used  Negative: no follow-up assessment post intervention, reliability and validity of outcome measures not demonstrated
Testad et al., (2010)	CRCT	Residents 145 4 nursing homes, Norway	Relation-Related Care training programme vs. Care as usual Single blind Intervention duration: 6 months Total training hours: 20 High intensity Supervision: None	CMAI (Norwegian version), proportion of residents given restraint  Baseline, 6 and 12 months follow-up	Sig between group differences in restraint use at 6 months (NR, p=.021), favouring the intervention condition, but no longer sig. at 12 months (NR, p=.57). Sig group by time interaction effect for aggression scores (CMAI) in favour of the intervention group (F= 3.46, p=.034).	1/4: Low quality	Positive: 12 month follow up, attrition described, blind assessors used Negative: power calculation and data analysis were not adjusted for cluster effects, groups not matched at baseline, no intention-to-treat analysis, randomisation method not described.

McCurry et al., (2012)	RCT	Residents 47 37 adult family care homes, USA	Sleep education training programme vs. Care as usual Single blind Intervention duration: 4 weeks	CSDD, RMBPC, ESS, actigraphy	Sig. between group differences, in favour of the intervention group, in percentage of sleep (Z= 2.05, p= .04) and sleep time (Z= 2.49, p=	3/4: Medium quality	Positive: 6 months follow up, Single blind assessors, intention to treat analysis Negative: length of training was not standardised, power analysis and randomisation
			Total training hours: 2.76 (average) Low intensity Supervision: Included in training sessions, time not specified	Baseline, 1 month and 6 months follow- up	.013) at 6 months. Sig. lower depression scores (CSDD) in intervention compared to control group (F= 9.61, p= .036). No sig. differences between groups in day time sleeping (ESS) or behavioural symptoms (RMBPC) (NR).		not described, validity and reliability of measures not demonstrated, small sample size
Testad et al., (2016)	CRCT	Residents 274 24 care homes, Norway	Trust Before Restraint training programme vs. Care as usual Single blind Intervention duration: 7 months  Total training hours: 16 Medium intensity Supervision: 6 hours	Use of restraint, CMAI, NPI, use of psychotropic drugs  Baseline and 7 months	No sig. difference between groups in restraint use (NR, p= .051), neuropsychiatric symptoms (NPI) (NR, p= .207), agitation (CMAI) (NR, p= .078) or use of psychotropic drugs (NR).	2/4: Low-medium quality	<u>Positive:</u> 7 months follow up, data analysis adjusted for cluster effects, single blind assessors <u>Negative:</u> randomisation method and reasons for drop out not described, validity and reliability of measures not demonstrated, no intention-to-treat analysis

Pieper et al., (2016)	CRCT	Residents 288  12 nursing homes, Netherlands	Stepwise multicomponent intervention vs. General nursing skills training Single blind Intervention duration: 3 months Total training hours: 15 Medium intensity Supervision: once a week, duration not reported	CMAI, CSDD, Dutch version NPI- NH, MDS- DRS, use of psychotropic medication  Baseline, 3 months and 6 months follow- up	Sig. lower depression (CSDD: NR, p< .001; MDS-DRS: NR, p< .001), agitation (CMAI) (NR, p= .02) and neuropsychiatric symptoms (NPI-NH) (NR, p= .005) in the intervention vs control group. Sig. reduced anti-depressant use in the intervention vs control group (NR, p= 0.046). No sig. difference in use of antipsychotics (NR, p= .38).	4/4: High quality	Positive: 6 month follow-up, data analysis and power calculations adjusted for cluster effects, blind assessors, randomisation described, intention to treat analysis used, reliability and validity of outcome measures demonstrated including for translated measure, Negative: groups were not matched at baseline
Lichtwarck et al. (2018)	CRCT	Residents 229  33 nursing homes, Norway	CBT and person-centred care training vs. Dementia education only Single blind Intervention duration: 8 weeks Total training hours: Intervention:8 Control: 2 Low intensity Supervision: First case conference observed.	NPINH, CMAI, CSDD, QUALID  Baseline, 8 weeks and 12 weeks	Sig. difference between groups in the change in agitation (NR, p=.006), disinhibition (NPINH) (NR, p=.032), depression (CSDD) (NR, p=.01) and quality of life (QUALID) (NR, p=.01) scores at 12 weeks and delusions subscale (NPINH) (NR, p=.028) at 8 weeks favouring the intervention group. No sig. group differences on other NPINH items.	4/4: High quality	Positive: Data analysis and power calculations adjusted for cluster effects, blind assessors, randomisation method described, intention to treat analysis used, reliability and validity of outcome measures demonstrated, Negative: longer term follow up would have been beneficial

Note. ADL = Activities of Daily Living; ADRQL = Alzheimer Disease Related Quality of Life; AGECAT = Automatic Geriatric Examination for Computer Assisted Taxonomy; AI-C = the Apathy Inventory-Clinician version; ASEP = Assessment Scale for Elderly Patients; BARS = Brief Agitation Rating Scale; BEHAVE-AD = Behave Pathology in Alzheimer's Disease Rating Scale; BPSD = Behavioural and Psychological Symptoms of Dementia; CAPE-BRS = Clifton Assessment Procedures for the Elderly – Behaviour Rating Scale; CAS= the Clinical Anxiety Scale; CBS = Challenging Behaviour Scale; CBT = Cognitive Behavioural Therapy; CMAI = the Cohen-Mansfield Agitation Inventory; CSDD = Cornell Scale for Depression in Dementia; DBRSP = Dutch Behaviour Rating Scale for Psycho-geriatric inpatients; DCM = Dementia Care Mapping; ERIC = Emotional Responses in Care; ESS = Epworth Sleepiness Scale; GDS = the Geriatric Depression Scale; GOS = a Group Observation Scale; GRGS = Geriatric Residents Goal Scale; MAX = Maximally Discriminative Affect Coding System; MDS-DRS = Minimum Dataset Depression Rating Scale; MOSES = Multidimensional Observation Scale for Elderly Subjects; NPI-Q = Neuropsychiatric Inventory Questionnaire; NPI-NH = Neuropsychiatric Inventory – Nursing Home; NR= test statistics not reported in paper: test statistics and p-values were included when reported; OS = Observation Scale; QOL-AD = Quality of Life in Alzheimer's Disease; QUALID = Quality of Life in Late-stage Dementia; QUIS = Quality Interactions Schedule; RAID = Rating Anxiety in Dementia; RMBPC = the Revised Memory and Behaviour Problems Checklist; TESS-NH = Therapeutic Environment Screening Survey for Nursing Homes; VPM= VIPS Practice Model.

Agitated behaviour. Fourteen studies investigated the effect of staff training programmes on agitated behaviour. Six of these studies found a positive effect of training on resident agitation, when compared to conditions (Chenoweth et al., 2014; Deudon et al., 2009; Lichtwarck et al., 2018; McCallion et al., 1999; Pieper et al., 2016; Rokstad et al., 2013). In order to measure this behaviour, the majority of studies used the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1991). Four of the studies that found a positive effect were rated as high quality (Chenoweth et al., 2014; Pieper et al., 2016; Lichtwarck et al., 2018; Roskstad et al., 2013) and one was deemed to be low quality (McCallion et al., 1999). Of the eight studies, that did not find an effect of training, one was rated as high quality (Fossey et al., 2006) and one was rated as low quality (Davison et al., 2007).

Chenoweth et al. (2014), in a high quality study, found that residents' agitation levels following person-centred training continued to be lower than the control group at a 14 month follow-up. The same result, however, was also found in a non-training, person-centred environment condition; suggesting that other factors, aside from staff training, can contribute to such improvements (Chenoweth et al., 2014). In support of this, Testad et al. (2016) failed to find a difference in resident agitation levels between the intervention and control group, as agitation scores improved in both conditions. This was attributed to wider cultural changes taking place, positively affecting care practices and, consequently, the need for training.

Challenging behaviour. Six studies evaluated whether staff training programmes reduced the challenging behaviours displayed by residents; two studies found a positive significant effect of training (Chenoweth et al., 2009; Teri et al., 2005). Additionally, one study found that this positive effect continued to be maintained at eight months (Chenoweth et al., 2009, high quality).

Aggressive behaviour. Two studies investigated the effect of staff training programmes on resident aggression. One study found a reduction in resident aggression in the intervention group compared to the control condition; a result that was sustained at the 12 month follow-up (Testad et al., 2010). Conversely, Visser et al. (2008) found no difference between the training only, training and peer support and control conditions in regards to resident aggression. Both of these studies, however, were rated as low quality and so results should be interpreted with caution.

Functional ability. Two studies evaluated the effect of staff training programmes on residents' functional ability. Wenborn et al. (2013) in a medium quality study, found that an occupational therapy training programme led to no significant changes in residents' ability to do daily routine activities relative to care as usual. Whereas, a medium-low quality study found that some, but not all, areas of residents' functional ability improved following practical BPSD management training (Leone et al., 2013). Between-group comparisons, however, were not reported in this study and therefore the results need to be interpreted with caution.

Psychological symptoms of dementia. Within this review, 17 studies measured resident psychological symptoms; 10 of these studies found a significant positive effect of staff training on the psychological symptoms of care home residents with dementia (Duedon et al., 2009; Finnema et al., 2005; Leone et al., 2013; Lichtwarck et al., 2018; McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016; Proctor et al., 1999; Rokstad et al., 2013; Teri et al., 2005).

**Depression.** Eleven studies investigated the effect of staff training programmes on residents' symptoms of depression and emotional blunting; eight of these studies found a significant positive effect of training (Leone et al., 2013;

Lichtwarck et al., 2018; McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016; Proctor et al., 1999; Rokstad et al., 2013; Teri et al., 2005). Three studies found that improvements in residents' depression symptoms continued to favour the intervention condition six months post-training (McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016).

Conversely, three studies found no significant difference in residents' depression scores when compared to the control condition (Chenoweth et al., 2014; Magai et al., 2002; Wenborn et al., 2013). The majority of studies measured depression using the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young & Shamoian, 1988). Chenoweth et al. (2014) highlighted that byproxy responses using this measure often underestimate the severity of residents' depression, which they proposed may have contributed to non-significant results.

Overall neuropsychiatric symptoms. Nine studies investigated whether staff training reduced residents' overall neuropsychiatric symptoms; all of these studies used variations of the Neuropsychiatric Inventory (Cummings et al., 1994; Cummings, 1997). Four studies found significant positive effects of BPSD focused training (Deudon et al., 2009; Lichtwarck et al., 2018; Pieper et al., 2016; Rokstad et al., 2013).

One high quality study found that the positive effects of training, on resident neuropsychiatric symptoms, continued to be significant six months after the intervention (Pieper et al., 2016). Another high quality study found a significant improvement on some items from the neuropsychiatric scale (agitation, disinhibition and delusions), when compared to the control group, but failed to find an

improvement on items that detected affective symptoms and psychosis (Lichtwarck et al., 2018).

Leone et al. (2013) found that the neuropsychiatric symptoms of residents increased after training, however this increase was no longer significant at the 17 week follow-up and comparisons to the control group were not reported. Another study, though, found between group differences in resident neuropsychiatric symptoms at follow-up in favour of the care as usual compared to the DCM training condition (Van de Ven et al., 2013). One explanation offered by authors of both studies was that staff participants were more aware of psychological presentations after training and so noticed signs they may have previously missed. Three studies found no significant difference between groups regarding the change in residents' neuropsychiatric symptoms (Chenoweth et al., 2009; Sprangers et al., 2015; Testad et al., 2016).

Anxiety. Two studies evaluated the effect of staff training programmes on residents' anxiety. One study found a positive effect on residents' anxiety levels favouring the behavioural-based training condition (Teri et al., 2005). In contrast, another behavioural-oriented training programme led to no significant improvement in residents' anxiety scores when compared to the control group (Wenborn et al., 2013).

*Emotional responses*. Two studies also looked at the emotional responses of residents with dementia following staff training. Chenoweth et al. (2014), in a high quality study, found no between group differences in the emotional responses of residents post intervention. Finnema et al. (2005), however, found that, when

compared to the control group, residents had a more positive self-image and improved emotional adaption following staff training.

**Summary.** Thirteen of the twenty-four studies reviewed found that staff training interventions had a significant positive effect on at least one measure of resident BPSD. Depression symptoms seemed to be the most responsive to staff training, with 73% of interventions measuring resident depression finding positive results. The positive effect of staff training, however, was not consistent across studies. Ten studies found no difference in resident outcomes between training and control groups and two studies found negative effects on resident outcomes following training (Leone et al., 2013; Wenborn et al., 2013).

The Effectiveness of Staff Training Programmes in Relation to the Theoretical Approach of the Programme

Training programmes using a behavioural orientated approach with person-environmental fit. Of the five studies in this category, one found a significant positive effect of training (Teri et al., 2005). The small scale study found positive effects following STAR, a behavioural staff training programme that involved a variety of teaching methods such as workshops, lectures, role-plays and discussions (Teri et al., 2005). STAR, although based on behavioural approaches, also included a range of topics such as communication, general dementia education and behavioural activation.

Three studies compared behavioural-based staff training to training and staff support and a control condition (Davison et al., 2017; McCabe et al., 2015; Visser et al., 2008), with McCabe et al. (2015) also employing a support only condition. They found no significant difference, regarding the change in resident BPSD outcomes,

between any of the intervention groups and control conditions. Both Davison et al. (2017) and Visser et al. (2008) proposed that these findings may have been partly due to organisational barriers to staff training; highlighting the important of programme feasibility.

Another behavioural based intervention also failed to find significant changes in residents' mood, anxiety levels or behaviour in favour of staff training (Wenborn et al., 2013). This training programme, although including some elements of social learning theory, was predominately focused on increasing residents' activity levels.

Training programmes focused on communication approaches. Of the three studies in this group, one study found improvements in resident outcomes favouring communication training (McCallion et al., 1999). McCallion et al. (1999) conducted a training programme centred on communication as well as general dementia education; the training also involved regular staff observations and feedback from the trainer. It is important though to note that the low quality of this study means that results should be interpreted with caution.

Neither Magai et al. (2002) or Sprangers et al. (2015) found significant differences between the communication training and control conditions regarding residents' BPSD symptoms at follow-up. Sprangers et al. (2015), however, did find that their training programme led to reduced caregiver distress among staff; they suggested that, in time, this may lead to improved resident outcomes.

**Training programmes based on person-centred approaches.** Three of the four studies in this category found a positive effect of staff training on at least one of the outcomes measured. One high quality study, found that both general personcentred care training and a more specific dementia care mapping training (DCM) led

to significant decreases in resident problem behaviours compared to care as usual.

These findings were sustained at an eight month follow-up (Chenoweth et al., 2009).

Conversely, another high quality study found significant improvements in resident's depression scores in one type of person-centred training (VPM), when compared to the control group, but not in the DCM condition (Rockstad et al., 2013). The authors suggested that, by encouraging resident perspective taking, VPM training was more effective in reducing depression symptomology, as it enabled staff to be more aware of the depressive symptoms expressed by residents, allowing them to act on these. This indicates that, despite being grounded in the same approach, training programmes can vary in their effectiveness depending on the style, content and method of the training.

One person-centred staff training programme led to no significant improvements in any of the outcomes measured compared to care as usual (Van de Ven et al., 2013). The authors adopted a pragmatic style of research, using fellow nursing staff, rather than researchers, to train other staff participants; as well as using a broad inclusion criteria. They suggested that this research methodology may have led to their lack of significant findings.

Training programmes based on emotion-orientated approaches. Of the two studies in this category, one study found a significant improvement in residents' BPSD outcomes following staff training relative to care as usual (Finnema et al., 2005). This finding, however, was only obtained for residents with mild to moderate dementia, and was not mirrored in residents with moderate-severe dementia. Unlike Finnema et al. (2005), Schrijnemaekers et al.'s (2002) study concluded that there was no evidence for the benefit of emotion-orientated approaches. Their study consisted

solely of individual's with moderate-severe dementia. They also proposed, as an explanation for their results, that this approach is not effective with individuals from this population.

**Training programmes based on practical BPSD management approaches.** Both of the studies in this category found a positive effect of staff training on at least one resident outcome. Deudon et al. (2009) found significant positive effects with regards to resident agitation and hyperactivity, whereas Leone et al. (2013) found a significant reduction in the level of emotional blunting displayed by residents. Both studies employed the same training programme design but focused on different symptoms, with Deudon et al. (2009) focusing training on resident agitation and Leone et al. (2013) focusing on resident apathy. These findings suggest that that this practical approach can be used flexibly, and altered depending on the needs of the residents.

Training programmes categorised as using other theoretical approaches. Of the eight studies in this category, five studies found a positive effect of staff training on at least one resident outcome measure compared to control conditions (Lichtwarck et al., 2018; McCurry et al., 2012; Pieper et al., 2016; Proctor et al., 1999; Testad et al., 2010).

Two of the training programmes found to be effective utilised multidisciplinary approaches (Lichtwarck et al., 2018; Pieper et al., 2016). The two studies, although using slightly different models, focused on the involvement of various disciplines in order to conduct a standardised and detailed assessment. Pieper et al. (2016) suggested that the use of multiple disciplines was particularly helpful for residents presenting with more complex symptoms. Mixed findings were obtained from the multiple studies that utilised an education and skills based approach. Two studies found a positive effect on some of the measures used (McCurry et al., 2012; Testad et al., 2010), whereas two studies found that resident BPSD outcomes did not differ at follow-up between the intervention and care as usual conditions (Testad et al., 2005; Testad et al., 2016).

Fossey et al. (2006) evaluated a training and support programme that utilised an integrated approach, involving a range of models including person-centred, communication and behavioural approaches. They found no effect of the programme on BPSD outcome measures. They did, though, find that, relative to usual care, the proportion of residents taking neuroleptic medication reduced following training.

**Summary.** There was no consistent evidence to suggest that the effectiveness of staff training programmes differed depending on the theoretical approach of training. The findings within each category were often variable, with no evidence to suggest that a particular theoretical approach was superior.

# The Effectiveness of Staff Training Programmes in Relation to the Programme Intensity

Low intensity staff training programmes. Of the ten training programmes lasting 10 hours or less (Davison et al., 2007; Lichtwarck et al., 2018; Magai et al., 2002; McCabe et al., 2015; McCallion et al., 1999; McCurry et al., 2012; Sprangers et al., 2015; Teri et al., 2005; Visser et al., 2008; Wenborn et al., 2013; ), four were found to be effective at reducing resident BPSD (Lichtwarck et al., 2018; McCallion et al., 1999; McCurry et al., 2012; Teri et al., 2005). All of these four programmes included an additional supervisory component, whereas two of the training

programmes not found to be effective included supervision (McCabe et al., 2015; Wenborn et al., 2013).

Some authors commented that the brief duration of training meant that it was more feasible, as it was easier for care home staff to attend training, it was more costeffective and, consequently, it was felt that it could be replicated in real world care home settings (Lichtwarck et al., 2018; Sprangers et al., 2015; Wenborn et al., 2013). In support of this, McCallion et al. (2009) found that the participating care home sites continued to utilise their communication training programme once the trial had ended, highlighting the feasibility of this low intensity intervention. Following the trial, however, booster sessions were added to the communication training programme, increasing the intensity of the intervention, suggesting that the previous duration had not been enough to sustain positive effects.

Medium intensity staff training programmes. Seven training programmes were categorised as medium intensity (11 – 19 hours) (Chenoweth et al., 2009; Finnema et al., 2005; Leone et al., 2013; Pieper et al., 2016; Proctor et al., 1999; Testad et al., 2005; Testad et al., 2016). Five studies within this category found a significant positive effect of staff training (Chenoweth et al., 2009; Finnema et al., 2005; Leone et al., 2013; Pieper et al., 2016; Proctor et al., 1999); three of these studies included a supervisory component (Chenoweth et al., 2009; Pieper et al., 2016; Proctor et al., 1999). Another study also included supervision within the intervention, but did not find any difference in resident BPSD relative to care as usual (Testad et al., 2016).

**High intensity staff training programmes.** Seven training programmes had a duration of 20 hours or greater (Chenoweth et al., 2014; Deudon et al., 2009;

Fossey et al., 2006; Rokstad et al., 2013; Schrijnemaekers et al., 2002; Testad et al., 2010; Van de Ven et al., 2013). Of these studies, four found a significant positive effect of staff training (Chenoweth et al., 2014; Deudon et al., 2009; Rokstad et al., 2013; Testad et al., 2010). Four of the interventions within this category included a supervisory component (Chenoweth et al., 2014; Deudon et al., 2009; Rokstad et al., 2013; Schrijnemaekers et al. 2002); only one of which was not found to be effective (Schrijnemaekers et al. 2002).

Schrijnemaekers et al. (2002) reflected that training programmes of this intensity were unusual in residential care practice, suggesting that such interventions may lack ecological validity and would struggle to be feasible in everyday care home settings. Testad et al. (2010), however, described their intervention as brief when compared to the intensity of staff's efforts to manage resident BPSD without training.

Summary. Proportionately, medium intensity training programmes (11-19 hours) were most likely to be effective, as 71% of medium intensity interventions were found to be effective compared to 57% of high intensity and 40% of low intensity programmes. Training effectiveness, however, was found to be variable within each category and with such small differences between categories, no one category can be deemed superior. There is evidence, though, to suggest that training programmes that included a supervisory component were more likely to be effective.

## Discussion

This review provided an update on the effectiveness of staff training programmes in reducing BPSD. The review evaluated whether staff training programmes

significantly reduce BPSD in care home residents with dementia. As well as whether the effectiveness of staff training programmes differs depending on the theoretical approach of the programme or the programme intensity.

### **Summary of findings**

Study quality. Twenty-four studies met the updated inclusion criteria and were evaluated in this review. The quality of these studies were variable, although it seemed that there was a general trend of improved quality over time. All four of the low quality studies, and the majority of the medium-low quality studies were published prior to February 2010, and therefore were obtained from the previous review. Conversely, the majority of the studies that were deemed to be high quality were more recent publications, with two-thirds of them published after 2010. Furthermore, it was observed that many of the recent studies referred to the CONSORT guidelines (Campbell et al., 2004) within the text, suggesting that there is a concerted effort to improve the quality of studies in this field. This would be welcome news for psychological care home research, which has previously been criticised for its weak quality (Kuske et al., 2007).

The effectiveness of staff training on resident BPSD. The studies reviewed looked at a large range of behavioural and psychological symptoms. The outcomes most commonly investigated were agitation, behaviour that challenges, depression and overall neuropsychiatric symptoms. Each study used a unique combination of outcome measures, although the Cornell Scale for Depression in Dementia (Alexopoulos, et al., 1988), the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1991), and the Neuropsychiatric Inventory (Cummings et al., 1994; Cummings, 1997) were commonly employed.

Thirteen studies found a positive effective of staff training on at least one outcome measure (Chenoweth et al., 2009; Chenoweth et al., 2014; Deudon et al., 2009; Finnema et al., 2005; Leone et al., 2013; Lichtwarck et al., 2018; McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016; Proctor et al., 1999; Rokstad et al., 2013; Teri et al., 2005; Testad et al., 2010). Additionally, six, out of the eleven studies that included longer term follow-ups, found that the positive effect of staff training was maintained at later assessment dates (Chenoweth et al., 2009; Chenoweth et al., 2014; McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016; Testad et al., 2010). These findings indicate that changes to care practices can be sustained in a care home setting, resulting in continued improvements in the wellbeing of residents.

It seems that, since the previous review (Spector et al., 2013), an increased number of studies have considered the impact of staff training on resident's psychological symptoms, in particular depression. Indeed, proportionately, this review found that staff training interventions were most effective at reducing resident depression. Rokstad et al. (2013) proposed that staff training can increase staff's awareness of the signs of depression, otherwise commonly missed in a care home setting, enabling staff to respond to such signals more effectively. It is noted, however, that three of the eleven studies investigating the impact of staff training on depression, did not support this finding.

The results in this review suggest that staff training can be an effective way of reducing resident BPSD, a finding that is supported by previous reviews (Livingston et al., 2014; Spector et al., 2013), however the evidence is variable. The positive effect of staff training on resident BPSD cannot be considered consistent, as a large minority of studies found no effect of training and some studies found

detrimental effects on resident BPSD following staff training. Furthermore, no single behavioural or psychological symptom improved across all of the studies reviewed and no consistency was found in regards to the type of symptoms that did improve following staff training.

This finding is supported by previous literature reviews, which also concluded that the effect of staff training on resident BPSD is inconsistent (Jutkowitz et al., 2016; Spector et al., 2013). These results could be due to wider systemic issues, with many of the studies describing difficulties with managerial support, staff availability and attrition, impacting upon intervention fidelity and effectiveness.

Managerial characteristics and care home ethos are likely to differ significantly between homes, meaning that the same training programme may be successful in some settings and not in others, leading to inconsistent results.

The impact of the theoretical approach of training. The studies reviewed were categorised into six theoretical approaches; behavioural orientated approaches with person-environmental fit, communication approaches, person-centred approaches, emotion-orientated approaches, practical BPSD management approaches and 'other' approaches. This review did not find any evidence to suggest that one theoretical approach was more superior to the others. The review also failed to find any evidence that any of the approaches were consistently effective; mirroring the finding of Spector et al. (2013).

The impact of training intensity on effectiveness. No conclusive evidence was found for the superiority of a particular training intensity. Proportionately, medium intensity training programmes (11-19 hours) were most likely to be effective, however the difference between the categories was small and variation was

found within each category. Spector et al. (2013) also failed to find any evidence for a particular training intensity but did suggest that medium intensity programmes were cost-effective and, unlike low intensity studies, did not risk being too brief, preventing the transfer of knowledge to staff. Medium intensity interventions are also more likely to be feasible, as opposed to high intensity interventions which have been considered problematic for staff to adhere to in such busy settings (Rappaport et al., 2017).

Fourteen of the studies evaluated included supervision sessions within the intervention. Of these studies, 71% found a positive effect on resident BPSD, suggesting that interventions that involved a supervisory component were more likely to lead to improvements in residents' symptoms. This result is supported by previous literature reviews which have also emphasised the value of supervision in staff training programmes (Spector et al., 2013; Rapaport et al., 2017). In their qualitative review, Rapaport et al. (2017) found that staff felt that supervision was important, as it enabled them to practice and get feedback on the new techniques they had learnt. It is therefore recommended that supervisory support should be included as a pivotal part of staff training, as to improve the effectiveness of these interventions.

#### Limitations

There are several limitations that need to be considered in this review.

Firstly, four of the studies evaluated were deemed to be of low quality and therefore the results of these studies should be interpreted with caution. The quality of such studies was acknowledged throughout the review, in an attempt to be transparent about this limitation.

Secondly, it is recognised that only 11 studies (Chenoweth et al., 2009; Chenoweth et al., 2014; Davidson et al., 2007; McCabe et al., 2015; McCallion et al., 1999; McCurry et al., 2012; Pieper et al., 2016; Schrijnemaekers et al., 2002; Testad et al., 2010; Van de Ven et al., 2013; Visser et al., 2008) had longer term follow-ups of six months or longer. This meant that it was difficult to evaluate the longer term benefits of staff training interventions, as more than half of the studies reviewed had not considered this.

It is also acknowledged that some methodology details are missing from a small number of the studies reviewed, such as the use of supervision. This makes is difficult to draw conclusions about the impact of training intensity. In an attempt to address this, the authors of these publications were contacted for clarification, as recommended by the York Centre for Reviews and Dissemination (University of York, 2009), but unfortunately no response was received.

The majority of studies used a CRCT design in order to prevent spill over effects from occurring between conditions. There were, however, issues with this approach, as some studies did not match the groups at baseline, meaning that later differences between groups may have been due to initial group differences rather than the effect of staff training. Some studies also failed to adjust their analysis to account for cluster effects, increasing the risk of type 1 error in these studies. All of the studies reviewed were qualitatively evaluated in line with CONSORT guidelines (Campbell et al., 2004) in order to address such methodological issues.

The modified Jadad scale was also used to assess study quality. This scale has been widely used within healthcare research and has been found to have the greatest evidence of validity when compared to other scales (Olivo et al., 2008). The

we of the modified Jadad criteria, however, has been discouraged by some (Alperson & Berger, 2013). The scale has been criticised for focusing too heavily on how studies are reported rather than the way in which they are conducted (Jüni, Witschi, Bloch & Egger, 1999). The brevity of the tool has also meant that some important methodological issues are missed (Olivo et al., 2008). Future reviews on the topic should consider employing an alternative, more in-depth, method such as Kmet's quality appraisal tool (Kmet, Cook & Lee, 2004). This tool, consisting of 14 items, has been shown to provide both a detailed and reproducible assessment of study quality (Kmet et al., 2004).

Finally, it is acknowledged that the studies differed in regards to levels of staff attendance and training completion, as well as wider organisational support. These factors are suggested to have an impact on the success of training and, consequently, resident outcomes (McCabe et al., 2015), but such factors were not considered in detail in this review.

#### Clinical implications and future research

The findings from this review have various important clinical implications. Recent government guidelines (Department of Health, 2012, 2015) have highlighted the need for further staff training within dementia care, however the results from this review indicate that not all staff training programmes are beneficial in regards to resident BPSD. This suggests that care home organisations need to carefully consider the training programmes delivered, ensuring that the interventions chosen have support from clinical trials.

Additionally, when delivering such interventions, individual resident factors need to be considered. Training programmes based on an emotion-orientated

approach were not found to be beneficial in improving the BPSD outcomes of residents with moderate-severe dementia (Finnema et al., 2005; Schrijnemaekers et al., 2002). This suggests that this intervention would not be beneficial for certain individuals or within certain residential care settings. In light of this, it is also recommended that future research should review the staff training interventions that are effective in reducing BPSD among individuals with more severe dementia.

It was also observed, as noted in the previous review (Spector et al., 2013), that very few of the studies evaluated published a manual for the training programme investigated. In order to ensure that care home staff have access to evidence-based training, as recommended by the UK government (Department of Health, 2012, 2015), the manuals for such programmes need to be disseminated alongside the research.

Future reviews on this topic would benefit from including a meta-analysis. This would allow a full integration of the findings reviewed (Borenstein, 2009), adding to the existing literature. A meta-analysis aims to assess the consistency of findings; this would be incredibly beneficial for reviewing staff training research given that the findings in this review have been variable. If a future review on the topic also concluded that findings were inconsistent then, unlike a narrative review, a meta-analysis would be able to measure the extent of the variance and the factors related to this (Borenstein, 2009).

Many studies described difficulties with the feasibility of staff training programmes, for instance staff struggled to attend training sessions and were consequently unable to implement complete interventions. Future research should explore the relationship between staff attendance and resident outcomes, as to

examine the impact of such feasibility issues. It is also recommended that future research should investigate more creative methods of delivering training programmes, as to ensure that such interventions remain feasible in busy care home settings.

Furthermore, although this review found an increase in the use of psychological outcome measures, there continues to be very little use of outcomes measuring anxiety related symptoms, with only two (Teri et al., 2005; Wenborn et al., 2013) out of twenty-four studies in this review considering this. Future research should aim to include such measures, so that the impact of staff training on resident anxiety can be fully explored.

Lastly, some of the articles commented on the dangers of relying on by-proxy measurements (Chenoweth et al., 2014; Wenborn et al., 2013), yet the majority of studies reviewed only used care giver reports. This highlights a potential difficulty in using existing measures with people with dementia. It would be beneficial for future research to consider the accessibility of current outcome measures for people with moderate and severe dementia, in an attempt to find means in which their views and opinions can be heard.

#### Conclusion

Overall, the findings from this review have indicated that staff training programmes can significantly improve the wellbeing of residents experiencing BPSD, but that the evidence for this effect cannot be considered consistent across studies. It seems that, of the various behavioural and psychological symptoms, resident depression is the most responsive to staff training, suggesting that this is a suitable intervention for this presenting problem. The results from this review have

also highlighted the value of supervision as part of staff training. Many of the studies evaluated, cited a lack of staff availability, managerial barriers and other organisational factors as the reason for their non-significant findings. Finding ways to improve the feasibility of interventions within residential care settings should be a priority, with the hope that doing so will lead to training programmes that are adhered to, sustainable and ultimately effective.

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# **Part 2: Empirical Paper**

SettleIN: Using a Manualised Intervention to Facilitate the Adjustment of Older

Adults with Dementia Following Placement into Residential Care

#### **Abstract**

**Aim:** The study aimed to examine the acceptability and feasibility of delivering an enhanced version of SettleIN, a manualised staff led programme designed to facilitate adjustment to residential care for new residents with dementia. The study also aimed to investigate the effectiveness of the programme in facilitating resident adjustment, as well as the effect on residents' mood and quality of life.

Methods: A pilot randomised control trial was conducted. A total of 19 new residents with dementia and 21 staff participants were recruited. Residents were randomly assigned to receive the SettleIN programme or treatment as usual. Resident quality of life, mood and overall adjustment were measured in both groups using self-report and by-proxy measures at baseline and at post-intervention, week seven. Interviews were conducted at week seven with staff who completed the programme to explore feasibility.

**Results:** Despite medium to large effect sizes, there was no significant difference in mean change scores between the two conditions, with regards to quality of life, psychological wellbeing or overall adjustment outcomes. The intervention was not feasible across all areas, particular issues were found with recruitment and practicality, however, SettleIN was feasible in terms of retention and acceptability among staff.

Conclusion: Qualitative feedback indicated that the majority of staff felt that SettleIN was beneficial for residents but that both organisational and programme factors impacted upon the feasibility of the intervention. A further feasibility study could address the issues described, requiring a re-structuring of the both the programme design and methodology.

#### Introduction

The trend of an aging population in the UK has been widely reported. It is estimated that 291,000 older people with and without dementia are already living in care homes in England and Wales (Office for National Statistics, 2014). By 2031, the number of older people predicted to reside in residential care homes, due to cognitive impairment alone, will increase to 390,000 (Comas-Herrera et al., 2011).

Research has suggested that there are various factors involved in the relocation to residential care, including; age, living alone, higher levels of carer burden, increased levels of frailty, as well as prevalence and worsening of dementia symptoms (Heppenstall, Wilkinson, Hanger, Keeling & Pearson, 2011; Toot, Swinson, Devine, Challis & Orrell, 2017; Yaffe, et al., 2002). Such circumstances can often mean that the transition into care is rushed and consequently best-practice guidelines are not followed. Many residents then feel powerless in the decision to move and experience negative outcomes as a result, including increased emotional responses and difficulties adjusting (Wilson, 1997).

# Adjustment to Care Homes for People with Dementia (PWD)

Adjustment is defined as 'the process of adapting or becoming used to a new situation' (Oxford Dictionaries Online, 2016). The focus of this paper is on the process of adapting to residential care. Evidence suggests that unsuccessful adjustment is common among people with dementia (PWD) (Ray, Ingram & Cohen-Mansfield, 2015). This is a concerning finding given that approximately 80% of people living in care homes in the UK are thought to have dementia (Alzheimer's Society, 2007). Unsuccessful adjustment is also associated with various negative outcomes (Hirschman & Hodgson, 2018).

The experience of moving into a care home has been linked with faster cognitive decline and reduced levels of cognitive functioning in PWD (Wilson et al., 2007). Research has also suggested that relocating into residential care has been linked to increased behavioural and psychological symptoms of dementia (BPSD) (Sury, Burns & Brodaty, 2013). Furthermore, residents have reported having a poorer quality of life following relocation from independent living (Scocco, Rapattoni & Fantoni, 2006). This finding, however, has not been consistently supported, suggesting that relocation does not need to negatively affect PWD and that successful adjustment is possible (Moon, Dilworth-Anderson & Gräske, 2017).

## **Facilitating Adjustment**

Aminzadeh, Molnar, Dalziel and Garcia (2013) proposed that in order to achieve successful adjustment PWD need to accomplish three processes: 'to settle in, fit in and find meaning in this transition'. Finding meaning and being accepted by others have been found to be important factors in fostering a sense of home for residents with and without dementia (van Hoof et al., 2016). Aminzadeh et al., (2013) suggested that to accomplish these processes residents must adjust to the schedule of the home, form new meaningful relationships and adjust their identity as they adjust to living somewhere new. However, the process of fitting in is especially challenging for those with dementia, as some of the impairments associated with the disorder, including communication difficulties, can make it harder to build connections with others (Aminzadeh et al., 2013).

Sury et al. (2013) conducted a systematic review to investigate factors that influence adjustment to residential care among PWD specifically. Their findings suggested that, when being placed into residential care, PWD benefit from having

some autonomy in regard to the decisions they make and the routine they have. The role of the physical environment, relationships, sociocultural needs and the presence of stimulating activity were also considered. This led to the recommendation of various strategies that could be utilised to aid successful adjustment including: orientation of the resident to the care home, using a buddy system with other residents and creating a home-like environment.

A later review further emphasised the importance of resident autonomy and decision making as well as the preservation of valued relationships in contributing to successful adjustment among PWD (Brownie, Horstmanshof & Garbutt, 2014). To facilitate adjustment, and consistent with Sury et al., (2013) various strategies, to be employed as part of routine care, were recommended (Brownie et al., 2014). In particular, the important role of care home staff was emphasised. Their position allows them to promote new relationships and encourage residents to discuss their experiences and life story, enabling connections to develop further. Staff training has consequently been proposed as a means of reflecting with staff on the emotional impact of relocation for PWD and ensuring that the strategies discussed are incorporated into every day care (Brownie et al., 2014).

Previous published interventions have focused on support for family caregivers during the adjustment period, rather than for the new residents with dementia (Müller, Lautenschläger, Meyer & Stephan, 2017). The research discussed above, demonstrated that there is a need for strategies to be developed into an intervention for new residents, that could facilitate successful adjustment, potentially improving residents' quality of life and preventing an increase of BPSD postadmission (Sury et al., 2013).

## The SettleIN Study

In response to this, Hayward, Nunez, Ballard and Spector (in press) created SettleIN, a person-centred tool for people with dementia that is designed to facilitate healthy adjustment. The staff led programme developed, was based upon adjustment literature (Aminzadeh et al., 2013) and the strategies suggested by Sury et al. (2013). A feasibility, pre-post measure pilot study was conducted (n=13), to evaluate the acceptability of SettleIN and explore the effectiveness of the programme in improving residents' mood and quality of life (QOL) ratings (Hayward et al., in press).

This study revealed that relevant stakeholders and staff who implemented the programme found SettleIN to be highly acceptable and enjoyable to use, demonstrating a strong foundation for the intervention. However, some staff found implementing the programme difficult due to their heavy work load and time constraints. The study did not find evidence to suggest that SettleIN, in its then existing form, was feasible to deliver in care homes across the UK. Due to high attrition rates of 62% (n= 5 post intervention), their study lacked sufficient data to draw conclusions about the effectiveness of the programme on residents' mood and OOL.

## **The Current Study**

Hayward et al., (in press) has demonstrated the acceptability of the SettleIN programme among stakeholders, which is key for an effective intervention (Craig et al., 2008). Research focusing on adjustment to care homes for those with dementia is sparse (Ray, Ingram & Cohen-Mansfield, 2015) and there are no publications about

other interventions having been created to facilitate this process (Müller, Lautenschläger, Meyer & Stephan, 2017). Additionally, the current lack of best practice guidelines for residents' initial few weeks of placement, highlights the need for research in this area. Therefore, to contribute to the knowledge base, a key aim of this study was to create a more feasible, enhanced version of SettleIN.

Recommendations for improvement by Hayward and colleagues were adopted in a second feasibility study. The programme was reduced and simplified and dependencies on those other than staff for delivery were removed in order to enhance feasibility. Staff feedback from the Hayward study also highlighted difficulties in engaging some residents and the consequent challenge of completing the programme with residents who were reluctant to partake in conversations with staff. Aside from resident communication difficulties, staff and authors considered that this was likely to be due to residents' difficult emotions about relocation. To address this, an optional module was added to the programme for residents who were struggling to engage.

The enhancements made were in line with recommendations from research evaluating the most beneficial components of psychosocial interventions within care home settings. This involved considering factors such as training intensity, the use of staff supervision and managerial support (Rapaport, Livingston, Murray, Mulla & Cooper, 2017). The study also expanded on the research carried out by Hayward et al. (in press) by including a control group; allowing natural adjustment to be measured and the effectiveness of the programme to be examined more clearly.

## **Aims of the Current Study**

The current study sought to investigate the effectiveness of the programme on facilitating adjustment among PWD who have recently been admitted into care homes within the UK. In the form of a pilot randomised controlled trial, the study examined the acceptability and feasibility of the enhanced version of SettleIN and whether staff implemented the intervention as intended. It was hypothesised that: a) those receiving the SettleIN intervention would experience an improvement in their mood and increases in their quality of life following programme completion compared to those in the 'treatment as usual' control group, and b) SettleIN would be feasible for staff.

#### Method

Guidance from the Medical Research Council proposes that interventions should be developed and evaluated using a four stage framework, consisting of: design and development, preliminary feasibility testing, evaluation and implementation (Craig et al., 2008). The study focused on the first two stages of this framework and was carried out as a joint project with Judy Murrill. This paper is focused on programme feasibility and resident outcomes, whereas Murrill focused on evaluating staff outcomes (see Appendix B). While both principal researchers led on programme development the process is only documented in this paper. The author was the principal researcher for data collection and Murrill led on staff training.

## **Phase One: Developing the Intervention**

The framework of designing, delivering and evaluating interventions is often not a linear one (Craig et al., 2008). Hayward et al. (in press.) found that the SettleIN intervention was not feasible for staff to deliver, leading the project to return to the development phase, for creation of a programme that was both feasible and effective.

Hayward and the principal researchers made the previously described enhancements and other modifications to SettleIN, which included reducing the intensity of the programme and formalising staff supervision. The later arose from consultation and are detailed below.

Consultation. Seven care homes involved in Hayward's trial, with experience of delivering the intervention, were invited to discuss the changes made to the programme. Of these, one care home manager agreed for two of their staff to meet with the principal researchers. Both staff members were care assistants who had delivered the programme in the previous trial.

The principal researchers met with the care assistants individually for approximately forty-five minutes. They were shown the enhanced SettleIN programme, following which the principal researchers conducted a semi-structured interview (see Appendix C). Written notes were made of the staff members' responses; see Table 1 for a summary. Following this consultation, further changes to the new SettleIN workbook were finalised ready for the feasibility study.

## Part Two: Feasibility Study of the Enhanced SettleIN Intervention

**Design.** The study used a between-subjects randomised experimental design to evaluate the feasibility of implementing an enhanced version of SettleIN. The study also focused on the effects of the SettleIN programme on new residents' QOL, psychological wellbeing and overall adjustment.

Table 1
Summary of consultation qualitative feedback

Theme	Feedback	Further changes made		
Programme intensity	<ul> <li>Reducing content made the programme more accessible</li> <li>Programme looked easier to do alongside job role</li> <li>There was too much to do in the previous version</li> </ul>	Some activity repetitions were reduced further		
Additions to the programme	<ul> <li>New activity added would work well</li> <li>New activity met resident's needs</li> <li>New module would be helpful for some but not all residents</li> <li>Supervision would be helpful</li> </ul>	Kept new module but made it optional  Agreed that supervision would be offered weekly		
Individual resident factors as barriers	<ul> <li>Resident personality and dementia severity, would influence programme feasibility and usefulness</li> <li>Programme dependent on resident's verbal ability</li> </ul>	Inclusion criteria to not include individuals with severe dementia as measured by The Functional Assessment Staging Test  To meet this criteria resident participants had to be able to speak more than 5-7 words a day		

**Ethical approval.** Ethical approval was obtained from both University College London Joint Research Office and the Camden and Kings Cross Research Ethics Committee (Ref: 15/LO/0611) (see Appendix D).

**Power calculation.** Calculations using G\*Power 3 (Faul, Erdfelder, Lang & Buchner, 2007) indicated that a sample size of 24 resident participants would be needed to obtain adequate power (0.8) at .05 statistical significance and to detect a conservative effect size of 0.3, chosen due to the lack of methodologically equivalent research. To account for possible attrition, the study aimed for a sample size of 30.

This was a pilot study, however, and therefore the chief aim was to assess feasibility for a full trial, retention rates and effect sizes.

#### Recruitment.

Setting. Between April 2017 and January 2018, 156 care homes were contacted to take part in the research. Care homes were identified using the Care Quality Commission (2013) care directory and the Enabling Research In Care Homes (ENRICH) database, a directory of care homes that have expressed a desire to participate in research. Opportunity sampling was also employed. The Chief Investigator's contacts from previous research and care homes involved in Hayward's research were invited to take part in the study.

Of the 156 care homes initially contacted, 10 care homes contacted the principal researchers expressing an interest in participation. The care homes that did not respond were contacted again by the principal researchers. From this an additional 17 care home managers expressed an interest in partaking in the research.

The principal researchers met with the care home managers from each of these 27 homes to discuss the study and to clarify that the home met the full inclusion criteria (see Table 2). Information leaflets about SettleIN were provided; see Appendix E for copies of the consent forms and information sheets used. In total, formal consent was gained from 17 care homes. All care homes were given a certificate for partaking in the research.

Table 2

Inclusion and exclusion criteria

Criteria	Setting	Residents	Staff	
Inclusion	<ul> <li>CQC rating of 'requires improvement' (that does not include safety as an improvement factor), 'good' or 'outstanding'</li> <li>Staffing levels to allow individual staff members leave to attend training</li> <li>Managerial support to participating staff</li> </ul>	<ul> <li>Dementia diagnosis</li> <li>Dementia classified as mild to moderately severe (stages 2-6) on The Functional Assessment Staging Test (FAST, Reisberg, 1987)</li> <li>Able to converse in English</li> <li>Relocated to the care home within the past month</li> </ul>	• Employed to support residents within the care home (may include Nurses, Health Care Assistants, Care Workers, Team Leaders, Activity Coordinators etc.)	
Exclusion	<ul> <li>CQC rating of         'inadequate' or a         rating of 'requires         improvement' in         which the safety         criteria is rated as         'requires         improvement'.</li> <li>Participation in any         other psychological         research study</li> </ul>	• Classified as having severe dementia (stage 7) on The Functional Assessment Staging Test (FAST, Reisberg, 1987)	Unable to attend training, assessments or deliver the programme	

Participants. In line with recent evidence about the importance of managerial support (Rapaport et al., 2017), a partnership approach was emphasised with all recruited care homes. This meant that as managers signed up to the study they agreed to take a key role in the running of SettleIN. Care home managers were encouraged to talk to new residents and carers about SettleIN as part of their routine process when discussing relocation. This allowed all new residents to be informed of the programme from the start, aiding recruitment. Staff then requested permission from the resident or carer for the principal researchers to contact them to talk about

the study further, at which point the researchers assessed suitability and sought formal consent (see Appendix D).

As the intervention was a staff led programme, the study required that there were one or two staff participants for every resident participant. Care home managers provided staff members with information leaflets about SettleIN, following which the principal researchers met with potential staff members to provide further details about the study and to obtain formal consent (see Appendix E). All staff participants were given a £10 high street gift voucher and a certificate for partaking in the research.

**Procedure.** Once consent was obtained from the staff participant, the resident (or their family), the baseline assessment was conducted.

Randomisation. Following baseline assessment, each resident was randomised to one of two conditions: the intervention group, which received the SettleIN programme, or the control group, which received treatment as usual. An independent researcher, separate from the study, randomised participants using a computer generated sequencing programme. Block Randomisation was employed, using a fixed block size of four, as to ensure an equal proportion of residents in each condition. After randomisation, the independent researcher informed the principal researcher responsible for training, of the new resident's treatment condition. The principal researcher responsible for data collection remained blind to the condition, ensuring that the study was single blinded.

#### Intervention.

Training. Staff participants, working with residents assigned to the intervention condition, attended a one to one training session on the SettleIN

programme, conducted by a principal researcher at the care home and lasting one hour and 15 minutes.

The training involved an introduction to adjustment theory and the factors that influence successful adjustment. The training systematically went through each module of the programme and covered how to deliver the individual tasks within modules, as well as how to complete the required documents used. Participants were given handouts of the training to take away with them (see Appendix F). Staff in the control condition did not receive training.

The SettleIN programme. The SettleIN programme is a staff-led manualised intervention designed to support resident adjustment. The intervention consists of four mandatory modules: orientation, lifestyle, friends and family and identity, as well as one optional module: for residents who struggle to engage. The modules are designed to promote healthy adjustment and are comprised of various activities to help achieve this.

All of the activities were carried out with the residents by staff participants, normally a resident's key worker, following which, the staff participant was required to document the relevant information in the workbook. More information on the modules, activities and associated worksheets can be found in the SettleIN workbook

The programme is designed to take a full time staff member four weeks to complete. It can take up to six weeks for staff who are on part time shift patterns. The programme ends with a brief future planning conversation; which is an opportunity to review adjustment progression with the resident.

**Measures.** Measures were collected from all residents and staff participants at two specific stages: baseline (week zero) and post intervention (week seven). The functional stage of dementia and demographic information was collected at baseline only. At week seven, 30 minute interviews were conducted with the staff participants who had received the SettleIN training and the SettleIN workbooks were collected to provide some information on implementation.

Demographics. Information regarding resident demographics (including age, ethnicity and religion) was obtained from residents' care plans. Relevant medical information, including prescribed medications, dementia diagnosis and recorded long term conditions, was gathered with informed consent from residents' medication charts and the medical history section of their care plans. For each participant this information was recorded on a demographics checklist created by the researchers (see Appendix G). Staff demographics (including age and years working in dementia care), usual care home adjustment support (support procedures such as a buddy system, orientation programme and any procedures to keep families informed of residents' wellbeing), and resident adjustment support (including prior visits to the home) were also asked about (see Appendix G).

Functional stage of dementia. The Functional Assessment Staging Test (FAST, Reisberg, 1987) was used to determine the functional stage of dementia for each resident participant. The staging tool considers instrumental physical tasks and activities of daily living in order to map the functional deterioration of individuals with dementia. The tool was completed with the staff participant. The FAST consists of seven main stages from normal functioning (stage one) to severe dementia (stage seven), with five sub-stages at stage six and six sub-stages at stage

seven. The FAST has been found to be both a reliable and valid assessment tool across all stages of dementia severity (Sclan & Reisberg, 1992).

Quality of life. Quality of life was measured using the Quality of Life in Alzheimer's disease (QOL-AD, Logsdon, Gibbons & McCurry, 1996). This 13 item measure is rated on a four point scale and consists of the following dimensions: participant's finances, physical health, mental health and social activities. The QOL-AD was completed by both the resident, where possible, and their keyworker. It has been shown to be a valid measure for individuals across all levels of dementia severity (Hoe, Katona, Roch & Livingston, 2005). The measure also has high levels of internal consistency for residents (Cronbach's alpha = .84) and by proxies (Cronbach's alpha = .86) (Logsdon, Gibbons, McCurry & Teri, 2002).

Psychological wellbeing. The Cornell Scale for Depression in Dementia (CSDD, Alexopoulos et al., 1988) was used to measure any improvement in mood; such improvement would be considered an indication of healthy adjustment. The CSDD consists of 19 items, which can be scored absent (0), mild/ intermittent (1) or severe (2). The CSDD was completed with both the resident, where possible, and their keyworker. The design of this measure allows for staff input and is therefore not dependent on resident completion (Williams & Marsh, 2009). The CSDD has been found to have strong psychometric properties including high inter-rater reliability and validity (Kørner et al., 2006). The measure has good internal consistency among residents with mild and moderate to severe dementia (Cronbach's Alpha= .81, .82 respectively) (Müller-Thomsen, Arlt, Mann, Maß & Ganzer, 2005); this is maintained when completed by proxy (Cronbach's Alpha= .86) (Wongpakaran, Wongpakaran & Reekum, 2013).

Overall adjustment. Adjustment was measured using the Index of Relocation Adjustment Scale (IRA, Prager, 1986). This consists of six items, which are measured on a four point likert scale with answers ranging from completely disagree (0) to completely agree (3). Total scores could range from 0 to 18, with higher scores suggesting better adaptation following reverse scoring on three negatively phrased items.

Hayward et al. (in press) adapted the measure to include facial expressions ranging from very unhappy to very happy; these were placed alongside the agreement levels previously stated. In this study, however, the measure was conducted as an interview and therefore the facial expression pictures were not used. This prevented the expressions from corresponding to a particular agreement level, which, on negatively phrased questions, could have been confusing for residents.

Previous research has indicated that this measure has strong psychometric properties, in terms of reliability and construct validity, for older adults without cognitive impairment (Cronbach's alpha = .86) (Bekhet & Zauszniewski, 2014). The psychometric properties of the IRA, however, have not yet been assessed with individuals with dementia. The use of the measure in this study was therefore explorative; Hayward et al., (in press) found it to be a useful measure for PWD. This brief measure was completed with residents only.

Feasibility of SettleIN for staff. The interviews focused on staff participants' views on delivering the SettleIN programme (see Appendix H). The principal researcher responsible for data collection carried out the interview, rather than the researcher responsible for training, in an attempt to reduce response bias.

Feasibility measures. To fully examine the feasibility of the enhanced version of SettleIN the following dimensions of feasibility were measured, as recommended by Bowen et al., (2009): acceptability, demand, implementation, practicality and limited efficacy testing; recruitment and retention were also considered (please see Table 3).

## Analysis.

Quantitative data. Data were organised and analysed using the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were conducted with regards to participant demographics. In addition, SPSS was used to compare data from the outcome measures (QOL-AD, CSDD, IRA) from both conditions across the two specified time points. When measures were obtained by both staff and resident participants a combined score was used for analysis.

Missing data. When residents were unable to complete QOL-AD and CSDD measures due to dementia related impairments, physical illness or personal preference, but remained in the study, by-proxy reports were relied upon as the sole source of information for these outcomes. The IRA cannot be completed by proxy, when residents were unable to complete this measure, for the reasons stated above, this outcome was not collected for those participants. Missing data due to attrition was analysed using a last observation carried forward approach. QOL-AD and CSDD measures were collected by proxy from staff participants even if the person ended up not receiving the intervention due to resident death; IRA measures were not collected following attrition.

*Qualitative data*. Interviews with staff were used to explore programme feasibility and acceptability. To protect confidentiality, the qualitative interviews

were transcribed verbatim and anonymised. Data obtained from staff interviews were analysed using thematic analysis. Analysis was carried out using the six phases recommended by Braun and Clarke (2006), this involved familiarisation with the interview scripts, generating initial codes from notable aspects of the interview data and then looking for broader patterns or themes among the different codes found. These themes were then reviewed and refined before being finalised. As part of the analysis, both principal researchers coded the data individually as to ensure that the codes generated were consistent with the data set.

Table 3

Key dimensions of feasibility examined and outcomes measuring this

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Area of feasibility	Related research question	How assessed
Acceptability	Is an enhanced version of	1) Consultation following
	SettleIN acceptable, attractive	modifications to SettleIN
	and satisfying to stake holders?	2) Staff participant interview.
		3) Descriptive statistics of
		recruitment feasibility
Demand	To what extent was enhanced SettleIN used?	1) Staff interviews
	Settletin used?	
Implementation	To what extent was enhanced	1) Analysis of SettleIN
	SettleIN successfully delivered?	documents
		2) Staff participant interview
Practicality	To what extent was enhanced	1)Staff participant interview
•	SettleIN carried out with	
	intended participants without	
	outside intervention?	
Limited efficacy	Is an enhanced version of	1) QOL-AD
·	SettleIN effective in facilitating	2) CSDD
	the adjustment of PWD who	3) IRA
	have recently been placed into	,
	residential care?	
Recruitment	How easy was it to recruit?	1) Number of contacts made
		2) Time taken to recruit
		3) Numbers recruited
		,
Retention	How many participants stayed in	1) Attrition rates
	the trial?	

Thematic analysis was used as it is a flexible approach that provides results which can be understood by the public (Braun & Clarke, 2006). This was crucial as the outcomes needed to be accessible to care home staff and carers. It is also a method commonly used to analyse interview data (Barker, Pistrang & Elliott, 2002).

#### Results

Between July 2017 and March 2018, care home managers informed the researchers of 42 new residents who had relocated into the recruited care homes (see Figure 1). Of these, the care home managers proceeded to discuss the research with 25 residents and their families. Twenty family members or residents expressed an interest in speaking to the researchers about the study. One family member declined participation on behalf of their relative due to concerns about the research intensity. In total 19 new residents from 12 care homes took part in the study. As two of the residents had an additional staff member involved, 21 staff participants were involved in the study.

## **Resident Characteristics**

A summary of residents' demographic characteristics can be found in Table

4. The age of resident participants ranged from 73 to 96 years. The majority were white British and spoke English as a first language. In total 74% of residents had an Alzheimer's diagnosis, as opposed to vascular or other forms of dementia.

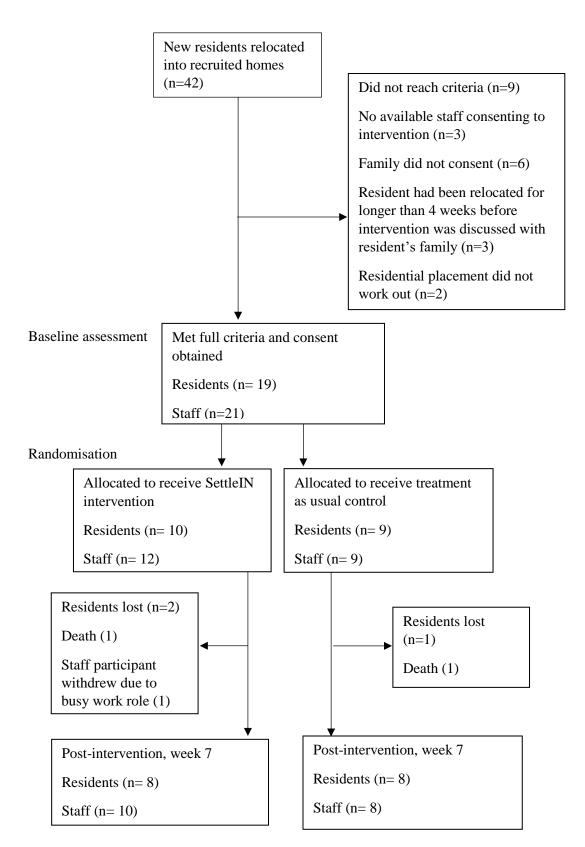


Figure 1: Resident participant flow chart

Table 4

Baseline resident demographic characteristics

Characteristics	Intervention condition	Control condition	
	(n=10)	(n=9)	
Age, mean (SD)	87.90 (7.20)	86.33 (6.58)	
Number of days since relocation, mean (SD)	17.00 (9.30)	17.11 (7.83)	
Gender, N (%)			
Female	9 (90)	7 (78)	
Male	1 (10)	2 (22)	
Ethnicity, N (%)			
White (British)	10 (100)	7 (78)	
White (Other)	0 (0)	2 (22)	
Religion, N (%)			
Church of England	3 (30)	5 (56)	
Catholic	1 (10)	2 (22)	
Jewish	3 (30)	0 (0)	
No religion	3 (30)	2 (22)	
First language, N (%)			
English	10 (100)	7 (78)	
Other	0 (0)	2 (22)	
Marital Status, N (%)			
Single	0 (0)	2 (22)	
Married	0 (0)	1 (11)	
Widowed	9 (90)	6 (67)	
Divorced	1 (10)	0 (0)	
Dementia diagnosis, N (%)			
Alzheimer's	7 (70)	7 (78)	
Vascular	3 (30)	1 (11)	
Other	0 (0)	1 (11)	
FAST score, N (%)			
Mild dementia	1 (10)	1 (11)	
Moderate dementia	1 (10)	1 (11)	
Moderately severe			
dementia	8 (80)	7 (78)	
Number of long term health conditions, mean (SD)	4.20(1.99)	3.00 (1.58)	
Number of prescribed medications taking, mean (SD)	7.70(3.68)	8.00 (5.07)	

The number of known long term health conditions ranged between one and eight, with residents taking between one and eighteen prescribed medications at the

time of baseline assessment. All but one of the residents had family members that were involved in their care.

Overall, 53% of resident participants were assigned to the intervention condition. There were no significant between-group differences at baseline with regards to residents' demographic characteristics.

# **Staff Participant Characteristics**

Table 5 shows a summary of staff participants' demographic characteristics. The majority were female and employed as care assistants, with the total number of years working in dementia care ranging from 9 months to 32 years. Their age ranged from 21 to 61 years. No significant between-group differences were found at baseline with regards to staff participants' demographic characteristics. Overall 57% were assigned to the intervention condition and received the SettleIN training.

Table 5

Baseline staff characteristics

Characteristics	Intervention condition	Control condition	
	(N=12)	(N=9)	
Age (years), mean (SD)	43.17 (13.72)	38.78 (12.85)	
Gender, N (%)			
Female	11 (92)	7 (78)	
Male	1 (8)	2 (22)	
Job title, N (%)			
Care Assistant/ Support			
worker	8 (67)	5 (56)	
Senior Care Assistant	1 (8)	2 (22)	
Team Leader	1 (8)	2 (22)	
Activities Co-ordinator	1 (8)	0 (0)	
Care Manger	1 (8)	0 (0)	
Years working in dementia, mean (SD)	9.88 (9.59)	7.97 (6.77)	

## **Current Adjustment Support**

All 12 care homes completed a checklist about the standard adjustment support they provided (see Table 6). None of the homes had a formal buddy system. Six homes showed new residents around on their first day but not as part of a continued orientation programme.

Table 6

Existing adjustment support used by recruited care homes

Adjustment support methods	Formally carried out with resident and family	Formally carried out with family only	No formal protocol but sometimes conducted	Not done
Buddy system, N	0	0	0	12
Orientation programme, N	0	0	6	6
Preferences asked about, N	7	5	0	0
Background information asked about, N	4	6	1	1
Life books, N	2	2	0	8
Procedures to keep family informed about adjustment, N	0	0	12	0

Relocation assessments were used as an opportunity to learn new information about residents. Seven homes used the opportunity to ask about residents' preferences and four used this time to ask about residents' background information. None of the homes had special arrangements to contact family members around the adjustment period, instead informal discussions took place when family visited unless there were urgent problems or following medical appointments. Five care homes also used additional methods to support adjustment including, introducing the resident to their keyworker, liaising with a resident's former GP and informing new

residents of activities taking place within the home; one home also created memory boxes with new residents.

All of the residents recruited had attended a relocation assessment prior to moving in to the care home. Two had a life book made, six were asked about their background information and 10 were asked about their preferences before joining the study. During post-intervention interviews, though, staff commented that these methods were not as in depth as the SettleIN tasks.

## **Missing Data**

In total six residents in the intervention condition and four residents in the control condition were unable to complete the QOL-AD and CSDD outcome measures at baseline; by-proxy reports were utilised for these participants. Of the residents who remained in the study but were unable to complete the QOL-AD and CSDD outcome measures at week seven, five residents were in the intervention condition and four residents were in the control condition. Again, for such cases staff by-proxy reports were used as the sole source of information; see Table 7 for a summary of resident missing data.

One resident in the intervention condition and one resident from the control condition did not complete the CSDD and QOL-AD measures at follow-up but were still able to complete the IRA. Additionally, one resident in the intervention condition was unable to complete the QOL-AD and CSDD at both baseline and follow-up but was able to complete the IRA at both time points. The IRA cannot be completed by-proxy and so adjustment data was not collected or analysed for residents unable to complete the measure.

With regards to missing data due to attrition, two resident participants were lost to follow-up in the intervention condition; one resident died and one was paired with a staff participant who withdrew due to work commitments. In the control condition, one participant was lost due to resident death.

Table 7

Missing resident self-report data by group and time point

		Interv	ention (n= 10	<b>)</b> )		Cont	rol (n= 9)		
	Base	line	Week 7		Base	Baseline		Week 7	
	QOL-AD/ CSDD	IRA	QOL-AD/ CSDD	IRA	QOL-AD/ CSDD	IRA	QOL-AD/ CSDD	IRA	
Unable to complete (n)									
Dementia related	5	4	4	3	2	2	1	1	
impairment									
Physical illness	1	1	0	0	2	2	1	0	
Personal preference	0	0	1	0	0		2	2	
Attrition (n)									
Resident death	-	-	1	1	_	-	1	1	
Staff withdrawal	-	-	1	1	-	-	0	0	
Total (n)	6	5	6	5	4	4	5	4	

## **Exploratory Analysis of the Efficacy of the SettleIN Intervention**

All data met the assumptions of normality required for independent samples t-tests, as assessed by the Kolomogorov-Smirnov test and z scores calculated for skewness and kurtosis. No outliers were identified in the data set. Change scores for CSDD and IRA measures met the assumptions of homogeneity of variance, as assessed by Levene's test. For the QOL-AD change scores, the variances were unequal for the intervention and control group, (F(1,17) = 6.66, p = .02). See Table 8 for a summary of mean scores at assessment points, mean changes scores and significance values.

**Resident psychological wellbeing**. On average the control group experienced more depressive symptoms, as measured by the CSDD, at baseline compared to the intervention group. This difference was not found to be significant, t(17) = 1.14, p = .27.

The mean change score in the CSDD scores was compared between groups. Although a large effect size was found in favour of the intervention group (d=0.70), independent samples t-tests indicated that this difference in mean change between groups was not statistically significant (t(17) = 1.45, p = .41).

Table 8

Mean pre and post scores, mean change scores and statistical significance

Characteristic	N	Baseline Mean (SD)	Post- intervention Mean (SD)	Mean change from baseline (SD)	P	Effect size
CSDD						
Intervention	10	10.60 (5.18)	8.20 (5.07)	+ 2.40 (5.52)	.17	0.70
Control	9	13.17 (4.57)	14.83 (4.30)	- 1.67 (6.69)		
QOL-AD						
Intervention	10	31.50 (5.21)	33.60 (6.17)	+ 2.10 (3.78)	.43	0.47
Control	9	30.83 (4.37)	30.78 (5.65)	- 0.06 (7.13)		
IRA						
Intervention	5	6.40 (2.88)	11.80 (4.67)	+ 5.40 (6.23)	.24	0.91
Control	5	8.00 (3.67)	8.00 (5.05)	0.00 (7.07)		

<sup>(+) =</sup> improvement (-) = deterioration

**Resident quality of life.** The change in QOL-AD scores was compared between groups. A medium effect size was found in favour of the intervention group (d=0.47), however, independent samples t-tests revealed that the mean change in QOL-AD scores was not significantly different between the two groups (t(11.88) = .81, p = .43).

**Resident overall adjustment.** At baseline, the intervention condition (n=5) had a lower mean rating of adjustment, compared to the control condition; this difference was not significant t(8) = -.77, p = .47.

The change in IRA scores between assessment points was compared between the two groups. A large effect size was found in favour of the intervention group (d=0.91), however, independent samples t-tests indicated that the difference was not statistically significant between groups (t(8) = 1.28, p = 24).

## **Feasibility**

Recruitment and retention. The researchers were unable to recruit 30 resident participants to the pilot study within the nine month time frame. There was a low uptake among care homes, with one in nine of the care homes contacted consenting to partake in the intervention. Within the recruited care homes, however, there was a reasonable resident uptake; approximately one in two of the newly relocated residents were recruited into the trial. The study had an acceptable level of attrition; three of the 19 residents and their corresponding staff participants were lost to follow up.

**Implementation**. All 12 staff participants in the intervention condition received one individual training session; the length of training was on average 75 minutes, but ranged between 60 to 90 minutes. The training and supervision sessions were conducted by the same principal researcher.

SettleIN workbooks were intended to provide information on programme implementation. Participants, however, were unable to fully complete SettleIN

documentation due to their work loads and time constraints. Implementation could therefore not be assessed in this study.

**Qualitative analysis of staff interview data.** Analysis of the 12 interview transcripts revealed five themes and 13 sub themes (see Table 9). See Appendix H for a complete summary of all themes and codes.

*Organisational barriers.* Ten participants spoke about organisational barriers having a negative impact on programme implementation. These barriers appeared to be divided into the following themes:

Existing heavy workload. Some described their job as "stressful" without the additional demands of the intervention. It seemed that implementing any programme on top of this felt like a significant addition.

"this job is very stressful. Very stressful" (P2A)

"care staff are inundated and under, sort of, are under it with their work pressures and their day to day routine and pressures" (P3)

Existing task focused approach. Participants often spoke about the multiple tasks that they needed to complete as part of their job role. This included care tasks, administrative duties and other training responsibilities. There was a sense that they were unable to dedicate time to a single resident as multiple residents needed their attention.

"I can't sit in one place and only do one thing because it's the work place"
(P9).

In particular, it was difficult to implement the programme during a morning shift, as participants were preoccupied with care tasks during this time.

"Most of the times I was there was during a morning shift, and that is umm really hard to slot in the times because you have your own break and then you have, you finish personal care around 11, and that's like, assisting 11 residents, and if there is still someone not up, you can't just go to do the programme, you have to keep going around" (P19).

To implement SettleIN some chose to prioritise the programme over their usual responsibilities or relied on the support of their colleagues. In some homes, there was the additional pressure of care tasks being electronically logged and then monitored. SettleIN was not recorded in this, so time spent delivering the programme was not seen by management.

Difficult to find the time. Many participants described their job role as 'busy'; they spoke about how this meant that they didn't have any free time in which they could do the programme or even take a break. In fact, a lack of time seemed to be the most common barrier.

"We don't have time to do here because we are all busy" (P2A)

The lack of time available to do the programme meant that several participants had to work on the programme outside of work hours, by coming in early, working during their breaks or working at home.

"I had to work overtime, to catch up with work I couldn't do" (P17).

Absence of managerial facilitation. Four participants described how managerial factors prevented them from implementing the programme. They reported that their shift was frequently located on a different care floor to the resident or that they were specifically allocated to other individuals rather than the resident participant.

"I am nearly always in the last stage of dementia, when (resident) is in the first stage... So I asked the nurses to put me in there, they did for the first week or so, umm, but then as the weeks progressed I was in there less and less often, so it was a lot harder to do any of the work" (P19).

Staffing provisions also seemed to be a problem, as low staffing levels meant that participants had more responsibilities.

"You know this time we got short staff. Maybe they're going to tell you could you do long day? Long day I start 7 in the morning and finish at half past 9. It's not easy." (P9).

**Programme factors acting as barriers.** Another theme that became apparent was that particular elements of the programme made it less feasible to deliver.

Documentation was challenging. Half of participants commented on the SettleIN documentation, describing it as "confusing", "difficult" and "stressful".

"The questions in there is good for our residents, you know? We do that one, but the problem is only the writing. It's very stressful." (P2A).

Table 9

Themes and sub themes from staff interview data

Themes	Sub themes
Organisational barriers	Existing heavy workload
	Existing task focused approach
	Difficult to find the time
	Absence of managerial facilitation
Programme factors acting as	Documentation was challenging
barriers	Inflexibility of programme structure affects programme completion
Individual resident factors	Dementia severity affected implementation
	Resident preference affected engagement
Acceptability of SettleIN	SettleIN is difficult for staff
	SettleIN content is acceptable to staff
	SettleIN is positive for residents
Overcoming challenges	External support is needed Adopting problem solving

The documentation was perceived to be time consuming and more challenging than actually delivering the programme. Not everyone found the documentation hard to do but there was an agreement that it was too lengthy.

Recommendations were made to reduce the volume of documentation or to move it on to an electronic format, a method of recording that was more familiar.

Inflexibility of programme structure affects programme completion. The weekly structure of the programme was seen as a barrier to programme completion to some participants. Outside factors such as annual leave, resident or staff illness meant that the programme was delayed and not completed within the four to six weeks.

"I wasn't able to complete all the things I am supposed to do in week one in week one, so it took me two weeks to finish week one itself." (P11)

One participant recommended that the programme should be more flexible as to accommodate these outside influences, aiding programme completion.

*Individual resident factors.* All of the participants who completed the intervention noticed that individual resident factors affected how easy it was to deliver the SettleIN programme.

Dementia severity affected implementation. Participants commented that it was more difficult to carry out certain programme activities in the context of more severe dementia. Dementia severity was perceived to affect residents' ability to remember personal information, understand the questions asked and communicate their answer.

"She listens to you, maybe she understood, because I cannot assume that she does not understand, but she is not responding back, just a smile" (P8A).

Some felt that the programme would be easier to deliver with residents whose dementia was less severe.

"I think this is focused on the early stages of dementia" (P11).

In contrast to this, though, one participant commented that it was not the severity of the dementia that mattered, but rather the skill set of the staff.

Resident preference affected engagement. Five participants expressed difficulties carrying out SettleIN activities due to individual resident factors

including mood, personality and physical wellbeing. It was sometimes difficult to have in-depth conversations with residents and on several occasions residents did not want to engage in conversation at all.

"It was challenging for me trying to engage with her even when she was in a really bad mood. Yeah that was a big challenge cos she was very 'no no no, I don't want to talk'" (P14).

Acceptability of SettleIN. All participants discussed their feelings about the programme. These differed but the majority, who described their concerns about the programme, also spoke about parts of the experience they had found satisfying.

SettleIN is difficult for staff. Four participants spoke about elements of the SettleIN experience that felt testing. Two of these talked about having initial difficulties with the programme, struggling to understand it or feeling overwhelmed by it, which delayed implementation.

"I would try and go through it and then I'd back away kind of thing. I found it quite daunting to get it up and running." (P3)

There was also a perception that others would find the programme difficult in the context of their busy work role, and one participant felt that, consequently, the programme was too lengthy for a care home setting. Two participants also spoke about finding some of the conversations with residents 'uncomfortable', and one participant felt that the programme would be difficult for staff who were 'not as chatty'.

"I didn't feel that comfortable to ask her those kinds of things... the more personal questions." (P11)

SettleIN content is acceptable to staff. In contrast, some described the intervention as "manageable" and "easy". Indeed, the majority spoke about their positive experiences of delivering SettleIN despite the challenges present. The programme was felt to be both "helpful" and "enjoyable", in particular, participants spoke about enjoying the opportunity for more in depth conversations with residents and working more closely with family members.

"It is nothing to not enjoy, because its, all the tasks, we are finding they are pleasant to do it, and I don't think they wouldn't' enjoy. And it is just for the benefit of knowing the person more". (P8A)

Participants also spoke about how much they got out of the experience, in regards to their own development. SettleIN provided them with an opportunity to be exposed to new experiences and to learn more; suggesting that there was a demand for the intervention.

"I think it is a good idea. I think it is best if you go round to homes and this sort of training will help people acknowledge more about dementia" (P6).

SettleIN is positive for residents. All of the participants who remained in the study until week seven felt that the programme had been of some benefit to the resident. The intervention helped them get to know residents more quickly and facilitated friendships with residents. Participants gave specific examples of changes they noticed in the resident as a result of the programme.

"Independence. Definitely. She'll still come and say something, you know 'where's my room' and I'll go 'you know where your room is (resident). You show me'. And off she goes ... You just stand up here with a silly grin on your face! Yeah! She's doing this!" (P13)

*Overcoming challenges*. Eight participants spoke about ways in which they had attempted to overcome the feasibility issues they faced.

External support is needed. Half of participants employed colleagues to support programme implementation. Some relied on others to complete care tasks whilst they delivered the programme. Those who conducted the programme in pairs found this to be particularly valuable.

"If you have partner, your colleague who you can ask, ask what do you understand about this, so they give you good ideas" (P8B).

Two participants expressed that more support was required from the researchers for SettleIN to be fully implemented.

Adopting problem solving. When challenges were present participants came up with various ways to try and solve these, in order to continue to deliver SettleIN. Solutions included planning ahead, relying on family members, being flexible with the programme structure and using alternative means to document SettleIN conversations.

"But as I said I have no time to write it down on the paper. But I have a list
... Yeah I kept it for myself because er.. I told before I don't have time to write
down" (P2B).

#### **Discussion**

This study aimed to develop and pilot an enhanced version of SettleIN, a psychosocial staff led intervention designed to facilitate adjustment to residential care for PWD. The study explored whether the intervention improved new residents' psychological wellbeing, quality of life and overall adjustment. In addition, it aimed to evaluate the feasibility and acceptability of SettleIN. Pre and post outcome measures were used to explore the efficacy of the intervention. Feasibility was measured through study uptake and staff post-intervention interviews.

# **Summary of Results**

**Efficacy of SettleIN.** Contrary to the initial hypothesis, and despite medium to large effect sizes, the change in scores between assessment points did not differ significantly between the two conditions for any of the three outcome measures employed.

Feasibility. SettleIN was found to be feasible with regards to staff acceptability and retention but not in terms of recruitment, wider organisational acceptability, and practicality. Only 19 resident participants were recruited after nine months, despite recruiting 17 care homes and contacting over 150. There was, though, a low attrition rate, with only three participants lost to follow up. The majority of staff participants, who took part in the intervention, spoke about their satisfaction with the programme content and the positive effects it had on residents. Organisational barriers, however, indicated that the intervention did not fit in with the wider care home culture and was therefore not acceptable on a broader organisational level.

There was conflicting evidence with regards to the demand of the intervention. Organisational and individual programme factors meant that implementation could not be assessed as intended.

Comparison to the first SettleIN study. The qualitative data from the first trial indicated that people found SettleIN to be too intensive in the context of organisational barriers. There were difficulties engaging particular residents in SettleIN tasks and the reliance on family members delayed the programme. In response to this, the current study reduced the length of SettleIN by removing the assessments surrounding the intervention and reducing the number of activities within each module. An additional module was added to support residents struggling to engage and all dependency on family was removed. A control group was also added to aid the exploration of the efficacy of SettleIN.

Despite these changes organisational factors remained a barrier to implementation and participants continued to comment on the impact of resident factors on programme implementation. In contrast to Hayward and colleagues' (in press) findings, however, only one participant commented negatively on the length of the programme. Family members were no longer relied upon to deliver the programme but some staff involved families in tasks, which was viewed as a positive experience. This study also found evidence that SettleIN was feasible with regards to retention, disconfirming Hayward who found high rates of attrition.

## Limitations

This study did not manage to recruit 30 participants as desired. The small sample size likely meant that it was underpowered to detect effects. A lack of power

increases the likelihood of type II error, possibly contributing to the non-significant results found.

The study's original design involved collecting data at three time points but due to recruitment challenges the one month follow-up had to be removed, reducing the assessments to two time points. The original power calculation was based on an ANOVA analysis but independent samples t-tests were actually conducted, questioning the validity of the power calculation. However, this was a pilot study and therefore full power was not expected; the main focus was on testing feasibility for a full trial rather than determining the effectiveness of the intervention.

The effect size measure Cohen's d was used to calculate the magnitude of difference between the two groups in regards to mean change scores. The use of Cohen's d is recognised as a limitation in this study because, although it is a widely used and standardised effect size estimate, it is positively biased when sample sizes are small (Cumming, 2013). As the sample size in this study was below 20, an alternative effect size measure, Hedges' g, would have been preferable. Hedges' g uses a pooled standard deviation to correct for bias in small sample sizes, providing a corrected estimate of effect (Cumming, 2013).

Due to the methodology of the study, contamination effects may have occurred between the conditions. Each resident was recruited individually upon relocation; individual, rather than cluster, randomisation was therefore utilised for ethical reasons. Staff were instructed not to discuss the programme with colleagues or to use the programme with other residents. It is likely though, that aspects of the programme would have been spoken about or observed, spilling over into the care of residents in the control condition.

The addition of the control group was one of the main strengths of this study, allowing the intervention to be compared to normal adjustment. While there were some differences between the clinical outcomes of the groups at baseline; these were not found to be significant. It is worth noting that care as normal can differ significantly between care homes and the treatment of residents in the control group may not have been homogenous. To overcome this issue, only care homes with a specified CQC rating were recruited. The routines, management and ethos of care homes were still likely to differ and such factors may have affected resident adjustment.

This study did not measure wider health variables including medication use and physical health status beyond baseline. During the course of the study, the physical health of residents was changeable, with two residents lost to follow up due to resident death. Anecdotal reports from some staff, during data collection, also indicated that at various points during the eight weeks residents experienced a decline in physical health, had brief hospital admissions or had an increase in medication. As discussed, unsuccessful adjustment is linked with various negative outcomes including reduced functional ability, increased mortality rates, (Ray et al., 2015) and increases in BPSD (Sury et al., 2013). These factors could therefore be considered indicators of unsuccessful adjustment. Unfortunately these variables were not recorded throughout the study. This meant that the relationship between residents' health outcomes and adjustment could not be explored.

Additionally, evidence suggests that a decline in the physical status of PWD can affect their mood (Rozzini, Boffelli, Franzoni, Frisoni & Trarucchi, 1996) and lead to confusion (Lyketsos, Sheppard & Rabins, 2000; furthermore, changes in medication can often result in side effects (Mintzer & Burns, 2000). These events

may have therefore, not only been an indicator of adjustment, but also influenced resident adjustment, as well as resident engagement in SettleIN. As the study did not measure these variables at follow-up, however, their effect on adjustment remains unclear.

The QOL-AD and CSDD have been shown to be valid measures for individuals with severe dementia (Hoe et al., 2005; Müller-Thomsen et al., 2005). The high proportion of residents unable to complete the measures in this study suggested that they are in fact challenging for such individuals to complete. This is a finding that is supported by recent research (Wenborn et al., 2013). Staff by proxy reports were therefore relied upon for some resident measures. Training, however, can alter how staff perceive residents' behaviour (Wenborn et al., 2013). Staff who received the SettleIN training will have learnt about the difficulties experienced by residents following relocation. These staff participants were perhaps more likely to notice such difficulties compared to staff in the control condition and so responded accordingly in the outcome measures.

It is also recognised that there are several limitations with the IRA outcome measure used. The measure has not yet been validated for use with PWD and so its use in this study was explorative. Furthermore, the adapted design of the measure included pictures of facial expressions corresponding to the various agreement levels. The measure was conducted as an interview in this study and so the expressions were not used, but if any residents had observed the measure, the facial expressions could have caused confusion on negatively phrased items.

In order to deal with missing data due to attrition, the last observation carried forward method was used. Although this is a simple and widely used approach, there

are some concerns that it can introduce bias into the results and lead to unjustified assumptions about the missing data (Streiner, 2002). This may have meant that the effect of the intervention was either exaggerated or minimised.

Furthermore, no formal measure of adherence was included in this study, which makes it difficult to determine whether staff in the intervention condition followed the programme as intended. The study was also unable to measure implementation as planned due to challenges with SettleIN documentation. It is therefore unclear whether the full benefits of the programme were achieved in this trial.

Thematic analysis was used to qualitatively explore staff interview data. Using interpretative phenomenological analysis (IPA) (Smith, 1996) could have provided more of an introspective study of staff experience. The IPA approach may have resulted in a more in-depth understanding of participants' personal perceptions of SettleIN and the feasibility of delivering it, whilst continuing to be a highly flexible method (Frost et al., 2010).

The resident sample had little ethnical diversity, with all of the residents categorised as white and the majority of residents considered to be white British. Previous research has indicated that care staff are more likely to label the behaviour of residents from BME backgrounds as challenging, compared to white residents (Wenborn et al., 2013). This highlights the need for the programme to be used with residents from every background, to help staff develop a psychosocial understanding of all residents in their care. The preconceptions held by some staff might affect how they deliver SettleIN and the choice of residents that the programme is offered to; this is an issue that requires further attention.

# **Implications for Future Research**

There are currently no publications focused on an intervention that facilitates adjustment to residential care for PWD. Sury and colleagues (2013), and Brownie et al., (2014) did, however, propose various strategies that could be employed to aid the adjustment process. The findings reported do not support their suggestions that such strategies result in significant change compared to treatment as usual.

These findings may be due to the feasibility issues present. This poses a dilemma as the qualitative feedback obtained indicated that a programme of this nature is needed, whilst also suggesting that the number of barriers to programme implementation was severe. A further feasibility trial could attempt to address this, however this would require re-thinking and re-structuring the design of the current programme. Researchers would need to return to the development phase of the Medical Research Council framework (Craig et al., 2008) to make changes to SettleIN in line with staff qualitative feedback. This would be a large undertaking and therefore would not be possible within the confines of a clinical psychology doctorate.

SettleIN documentation would need to be simplified and condensed.

Reducing the programme content during the development phase of this study meant that the programme was more acceptable; similar results may therefore arise from reducing SettleIN documentation. This is in line with recent research that has found that training programmes of reduced intensity are more satisfactory to staff (Rapaport et al., 2017).

The structure would also need to be adapted to make it more flexible. A possible solution would be to make some of the activities optional or to extend the

four week framework. This could reduce the likelihood of disruptions, which are likely to occur in this setting, from negatively affecting programme completion.

Participants spoke about the need for additional support to help deliver the intervention, indicating that it was not practical to deliver without outside help. To address this, staff could be trained in pairs to help with increasing programme flexibility. If another feasibility trial were to take place, it would also be key to involve the managers from the current study in the design phase of the trial. This would mean that organisational barriers, which are likely to continue, could be considered during programme development, with the aim of reducing their impact on programme completion. A greater focus on recruitment would also be needed, as to increase the sample size and power of the study.

Future research should also examine whether the programme is feasible with regards to cost. This was not considered in this study but would be an important issue to evaluate. It would also be beneficial to consider alternative ways of measuring implementation and adherence, aside from staff self-report measures.

There is a need for further research to focus on the validity and accessibility of outcome measures for people with dementia. Many residents struggled to complete the measures used in this study, which meant that valuable information about resident experience was lost. Creating measures that are more accessible would allow us to gain more insight about the usefulness of interventions from the perspective of the individuals that they are designed for.

Future research also needs to examine the most effective ways of supporting care home organisations to partake in research more generally. A review specifically focusing on effective, evidence based ways of overcoming organisational barriers

would be a helpful step in improving the feasibility of interventions within a care home setting.

# **Clinical Implications**

This study has contributed to the growing field of adjustment literature. By focusing on resident wellbeing, it has furthered the knowledge base about the adjustment process for people with dementia; an area that has previously been overlooked. This study has highlighted the negative impact that relocation can have on residents' psychological wellbeing, as over half of residents met criteria for depression at baseline. It seems that there is a need for adjustment support to be imbedded into care practice, yet the data indicated that, although, some adjustment support is currently offered by care homes for PWD, it is minimal and often targets family members, rather than the resident themselves.

When delivering the psychosocial intervention, the majority of staff felt that they developed a stronger, more positive relationship with new residents and that the programme provided support and comfort to residents during a difficult period.

These results point to the usefulness of staff led psychosocial interventions for new residents, but refer to factors that were perhaps missed when using quantitative outcomes. The organisational barriers present, however, showed the negative impact that heavy workloads and consequent time constraints, have on care staffs' ability to deliver psychosocial care on top of routine care tasks.

These organisational issues, alongside individual programme factors, meant that SettleIN was not feasible to deliver as part of standard care, reflecting the findings of Hayward. It was hoped that making changes to SettleIN, in line with the literature, would reduce the impact of such barriers. It seems, though, that there

continued to be a challenge in fitting these strategies into everyday care. This is an issue that would need to be addressed, if such strategies were to have a positive impact and lead to significant changes in the wellbeing of PWD.

# Conclusion

Overall the changes in resident's quality of life, wellbeing and overall adjustment following SettleIN, did not differ to treatment as usual. The programme was not found to be feasible in its current format, however, qualitative data suggested that the intervention was acceptable to the majority of staff and beneficial in some way for residents. Interviews with staff highlighted barriers to programme implementation stemming from organisational, resident and programme factors. A further feasibility study might wish to explore these factors further, although as discussed significant changes would have to be made to the programme prior to this. More broadly, an increased focus is required on reducing organisational barriers in care home research, so that such factors do not prevent programme implementation and changes to care practice from taking place.

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# Part 3: Critical Appraisal

## Introduction

This paper focuses on my reflections on the process of piloting a staff led intervention in a care home setting. The study, described in part two, involved developing, delivering and evaluating the SettleIN programme. The Medical Research Council (MRC) framework is widely utilised to aid this process; Craig and colleagues (2008) suggested that this framework protects against full scale trials being weakened by feasibility issues including adherence, acceptability, implementation, retention and recruitment. Such issues can result in underpowered trials, inappropriate research designs and ineffective interventions. Trialling complex interventions can be an extensive process and several pilot studies are likely to be needed before a full scale trial can be conducted (Craig et al., 2008). This paper will consider the dilemmas and barriers that were present at each stage of this pilot study, and the feasibility issues that will need to be overcome to enable a full scale trial of the SettleIN intervention.

# **Developing the SettleIN Programme**

As described in part two, due to the concerns about the feasibility of the previous version of SettleIN (Hayward et al., in press), and consistent with the MRC framework (Craig et al., 2008), this study re-visited the intervention development phase before moving on to feasibility testing. We hoped that developing an enhanced version of SettleIN would allow us to make improvements to the programme in line with the qualitative feedback received. This is crucial, as MRC guidelines suggest that variations of an intervention should be piloted and the content agreed upon prior to a full scale trial (Craig et al., 2008).

# **Enhancing Programme Content**

When re-designing the intervention there was a tension in striking a balance between theory and feasibility. We were aware from the qualitative data of the previous study that the programme felt too long and too intensive for staff participants. Literature has demonstrated that high intensity interventions are deemed to be problematic by staff in care home settings (Rapaport, Livingston, Murray, Mulla & Cooper, 2017). There was a concern though that, if we cut out too much to make it more feasible, the programme would no longer be in line with adjustment theory.

The involvement of family and friends in the programme was a clear example of this. The feedback from the previous study highlighted that depending on family members to complete certain activities delayed the programme as many family members were not present at the homes regularly. Adjustment theory, however, proposes that feeling abandoned by family members can prevent healthy adjustment from taking place; whereas facilitating connections between residents and their family, can protect against unsuccessful adjustment and feelings of loss (Ray, Ingram & Cohen-Mansfield, 2015; Sury, Burns & Brodaty, 2013; Thein, D'Souza & Sheehan, 2011).

The volume of research on the benefits of family involvement meant that we could not remove this element completely but neither did we want to ignore the incredibly valuable insights from staff experience. The model of knowledge translation emphasises the importance of an interactive relationship between researchers and stakeholders, in which ideas are shared rather than dictated by the researcher (Baumbusch et al., 2008). In line with this model, we felt that taking a collaborative approach with the staff participants, and users of research, would be most beneficial in order to ensure that the programme was acceptable to staff and

consequently increase the likelihood that the intervention would be implemented in care practice (Baumbusch et al., 2008). It was therefore agreed that we would keep the family and friends module but reduce the number of activities within this module; the activities were also altered so that they did not depend on family involvement if this was not possible.

#### **Stakeholder Consultation**

Once a draft of the enhanced programme was completed it was important that a stakeholder consultation took place to discuss the changes made. As this was the second trial, there was an opportunity to consult with staff members who had direct experience of delivering the SettleIN programme. I felt that a consultation with these individuals would be a real strength of this study, as it would offer an opportunity to exchange knowledge about the intervention and the practicalities of delivering this, ensuring that meaningful changes were made (Baumbusch et al., 2008). Indeed, understanding the context of an intervention is key to ensuring that an intervention is deemed accessible by those delivering it (Craig et al., 2008), a key feasibility concern in the previous trial.

Staff availability, though, presented as a significant barrier to staff consultation. It is widely recognised that there is a high staff turn-over rate in the care home sector (Hussein, Ismail & Manthorpe, 2016); we found that in the year since the previous trial had ended many of the care homes involved had changed management and many of the staff members had left. This prevented us from meeting with staff participants in six out of the seven homes. New managers were not keen for us to meet with staff, especially as they had no knowledge of the programme and did not have a relationship with the research team. Staff turn-over

also meant that, in the one home that consented to consultation, there were only two staff members with experience of SettleIN available. This was incredibly frustrating, as it felt that we were losing valuable knowledge that could have been used to improve the programme.

It seemed that relying solely on previous staff participants significantly limited the number of people we could consult with but it felt important to review the enhanced programme with these experts by experience. In an attempt to ascertain whether the enhanced programme was more feasible, without a large consultation, we studied the qualitative feedback from the first trial, as to ensure that our changes were in line with their suggestions. This, alongside the consultation with the two previous staff participants, formed the basis of our consultation process.

In order to improve the feasibility of the programme for a full scale trial this process will need to be more extensive. Future consultations should involve care home staff, managers, residents and family members involved in the current trial, as to ensure that the programme is deemed acceptable to all stakeholders involved.

## **Recruiting for the SettleIN Programme**

Once the development phase of the project was complete, the focus shifted to recruitment. Craig and colleagues (2008) emphasised that before moving on to a full scale trial, the researchers need to be able to make assumptions about recruitment rates and be sure that the sample sizes needed are obtainable.

## **The Recruitment Process**

The recruitment process for this study was incredibly challenging,
particularly when set within the time limits of the clinical psychology doctoral
programme. The process was lengthy and consisted of multiple stages; recruiting

and gaining consent from managers, individual residents and/ or their family and staff participants.

Recruiting care homes was an extensive undertaking, with the majority of care homes needing to be contacted on multiple occasions before initial contact was made. Care home managers were very difficult to reach and response rates to the original letters sent were low. There were also several occasions in which managers were unavailable on the day of scheduled meetings and so meetings were cancelled without prior warning.

# **Response from Care Home Managers**

Once in contact with prospective care home managers, though, there was a consensus that there was a demand for research in this area, as managers recalled various difficult experiences with resident adjustment. Managers identified a gap in their knowledge of how to manage this difficulty and were keen to receive support in this.

Many care home managers expressed concerns about staff provision and the impact on care of staff members being absent to complete questionnaires or attend training. A lack of staff availability has been a common barrier in care home research, with many studies evaluating staff training interventions citing it as a limitation and concern (Davison et al., 2007). For a full evaluation of the programme to take place, though, it was imperative that staff could receive adequate and standardised training.

# The Role of Managerial Support in Recruitment

Davison and colleagues (2007) proposed that in order to reduce such organisational barriers, a greater emphasis needs to be placed on managerial support from the outset. The inclusion criteria of the study therefore included managerial support and sufficient staff provision; these conditions were also discussed with care home managers at recruitment meetings. This decision may have meant that fewer care homes were able to partake in the research, but it was hoped that fewer organisational barriers would be present in the homes that did consent.

Once care homes managers consented, as part of the partnership approach taken, it was agreed that the manager would discuss the study in relocation meetings with new residents and their family members. Some managers found this to be a useful opportunity to discuss the study, other managers, however, felt that the family members would be overwhelmed at such a stressful time. Indeed, the process of having a relative move into residential care is linked with carer stress and anxiety (Bramble, Moyle & McAllister, 2009).

This presented as a challenge, for the researchers, as managers often struggled to speak to family members on other occasions. Other staff were preoccupied with care duties and did not have as much knowledge about the study to discuss the research with carers. This meant that the researchers were spending a significant amount of time chasing up referrals and that on three occasions resident recruitment opportunities were lost because family members were not spoken to within the resident's first four weeks.

A proposed solution for this dilemma could be for researchers to spend more time in the care homes so that staff members, other than management, become familiar with the research and the research team. The staff would then able to

discuss the study with new residents and their family members at a time which was more convenient. This was unfortunately felt to be beyond the scope of the clinical psychology doctorate, due to the time limits imposed.

### The Role of Wider Social Factors

The socio-political climate may have also influenced the recruitment process for this study. There were several care homes that consented to the research but did not have any new residents with dementia in the nine months of recruitment despite having vacancies. Other managers, who did refer some residents to the study, expressed that in previous years they would have been able to refer more residents. Anecdotal comments were made about reductions in local authority funding for care home providers negatively affecting staffing levels and the uptake of placements in care homes; a significant concern for care home managers.

## **The Inclusion Criteria**

The inclusion criteria presented as another barrier to resident recruitment. Many individuals living with dementia are not diagnosed as having the disease (van den Dungen et al., 2012), it is therefore common for residents to present with the symptoms of dementia without a formal diagnosis. This study only accepted those, though, who had received a formal diagnosis from a health care professional. This decision was made for ethical reasons, as the SettleIN documents given to relatives used the term dementia; giving these documents to individuals, when no diagnosis had been made, may have caused distress. Additionally, without a formal diagnosis the inclusion criteria for residents would become more subjective, reducing the reliability of the study.

This prevented several new residents from partaking in the study, as care homes attempted to refer new residents who experienced symptoms of dementia but had not received a diagnosis. In future, being less stringent about a formal diagnosis may facilitate recruitment and would allow more individuals to trial the programme. The terminology employed in the study documents for family members could be revised so that they do not include diagnostic labels, like the documents used for residents. A validated diagnostic tool could also be used by the researchers to ensure that resident inclusion was not merely subjective.

There are currently no published interventions for people with dementia (PWD) focused on facilitating adjustment to residential care (Müller, Lautenschläger, Meyer & Stephan, 2017); recruitment feasibility is perhaps a contributing factor in this. The amount of resources and time needed to recruit for this study leaves one questioning the feasibility of a full scale trial unless changes are made to the recruitment process, such as the ideas proposed in this paper. This perhaps goes to show the difficulty of recruiting participants during a time of crisis and upheaval, in which strict time limits are imposed. It is worth noting though, that by the end of this current trial, the process of recruitment became an easier one. Recruitment may therefore be more feasible for further trials if we continued to work with the homes that, through this trial, we have established working relationships with.

# **Delivering the SettleIN Programme**

In order for interventions to be deemed feasible, and therefore fitting for a full scale trial, we need to be confident that during feasibility testing the intervention was implemented, adhered to and acceptable to those involved (Craig et al., 2008).

# The Impact of Organisational Barriers

Staff feedback suggested that organisational factors made programme implementation challenging. It seems that the task focus approach employed by many care homes (Savundranayagam, 2014), may have been a barrier. When interactions within care homes are orientated to the care tasks that need completing, residents' psychosocial needs can often be overlooked (Chenoweth et al., 2009). The SettleIN intervention is very much focused on a resident's psychosocial needs with regards to adjustment, as such the programme was perhaps less likely to be prioritised in the more task focused homes, and consequently organisational barriers, such as lack of staff availability, reduced managerial support and reduced participation among the wider staff team were more likely to occur in such settings.

Organisational barriers also affected staff's acceptance of the intervention. In the qualitative interviews staff spoke about not having enough time to do the programme. They reported that staff shortages and difficulties getting breaks made the programme feel 'stressful' to deliver on top of other care duties. This is perhaps where staff supervision can be really valuable, as it enabled the staff participant to discuss these concerns with the researcher and, when needed, meant that the researcher could intervene with management, ensuring that managers were reminded of their responsibilities in the study. Not all staff, however, were available for regular supervision sessions due to their heavy workload, highlighting the importance of organisational support.

It was noticed that in some homes, however, the manager fully embraced their supporting role and organisational barriers such as low staffing levels were not present. This difference in organisational support between homes perhaps contributed to the highly contrasting staff feedback, with other staff participants finding the programme both enjoyable and manageable. This highlights the

significant variation between care homes and the impact that organisational factors can have on intervention feasibility within such settings (Davidson et al., 2007). It is clear that, prior to a full trial, future pilot studies of SettleIN will need to include ways of facilitating organisational support, in order to overcome the feasibility issues of implementation, adherence and acceptability.

# **Improving Research Understanding to Aid Implementation**

Further psychoeducation to care home management and staff on the importance of dementia care research could be beneficial. Recent government policy has urged that more care organisations participate in dementia research (Department of Health, 2015), it is therefore increasingly important that care homes are prepared for and fully understand the necessity for research, in order for this to be a success.

Conversely, with the current socioeconomic climate, even if managers fully understood their role in the research process, they may not be able to deliver the time and resources needed to trial a staff led intervention. Additionally, managers that do agree to commit to the project for the purpose of a research trial would not necessarily be able to extend this to everyday practice. Such concerns highlight the importance of individual programme factors when investigating feasibility and the need to consider these as well as organisational factors when trialling new interventions.

# **Programme Factors as Barriers to Implementation**

It was observed that in some homes there were tensions among care staff when staff participants were not available because they were completing the programme. It was hoped that much of the programme could be done during care

tasks, as to avoid this issue, but the writing involved in the programme meant that for many staff participants this did not feel possible.

This element of the programme may not have been accessible to all staff participants; it may have not have catered for the significant variation in educational levels among care assistants (Beck, Ortigara, Mercer & Shue, 1999). The writing component of SettleIN provides a compilation of evidence of all the work completed with the resident and was designed so that it could be used within the resident care plan, something that was reported to be helpful from staff participants in the previous trial (Hayward et al., in press). In order to further programme feasibility, this part of SettleIN is an example of individual programme factors that will need to be reviewed to make the programme more accessible to staff, easier to implement and more possible for staff to adhere to.

## **Evaluating the SettleIN Programme**

A mixed method approach was chosen for evaluating the SettleIN programme, as MRC guidelines recommend that qualitative data should be collected during initial feasibility testing, to aid understanding of implementation functioning and experience (Craig et al., 2008). Quantitative results are also needed to demonstrate that a study has limited efficacy, prior to a full scale trial.

## **Barriers to Evaluation**

Resident factors. The study failed to demonstrate the effectiveness of SettleIN programme, an important feasibility criteria (Craig et al., 2008). It's possible that external variables may have affected the results found, such as the high prevalence of physical health difficulties among residents (Mintzer & Burns, 2000). The design of our study meant that we were involved with residents for eight weeks,

from baseline to post intervention. Throughout this period some of the residents experienced declines in their physical health, which resulted in residents requiring short hospital stays, having to spend more time in their room away from other residents or needing new medications.

Changes like these can affect a resident's mood (Rozzini, Boffelli, Franzoni, Frisoni & Trarucchi, 1996), new medication can cause side effects (Mintzer & Burns, 2000), and environmental changes, like brief hospital admissions, can lead to confusion in PWD (Lyketsos, Sheppard & Rabins, 2000). Interview data from staff also suggests that these difficulties affected resident's engagement in the SettleIN programme and consequently the usefulness of the intervention. Regretfully, these confounding factors were not considered in the statistical data analysis but analysis of the qualitative data has highlighted the need for the programme to be more flexible in order to accommodate disruptions or delays caused by resident ill health.

The presence of physical health difficulties and consequent low energy levels among resident participants posed an additional barrier to data collection, as on several occasions residents felt unable to complete assessments at the time of the scheduled visit. Data collection visits, consequently, had to often be rearranged multiple times. These situations left us in a dilemma, stuck between wanting assessments to remain at weeks zero and seven, but not wanting to lose out on resident data.

Residents' self-report data is so valuable; it allows us to gain a more accurate understanding of their experience of adjustment, something that very little research has focused on (Thein et al., 2011). I therefore tried to prevent missing out on this by being as flexible as possible in the times and days I could visit, this was

appreciated by residents and staff, however for some residents data collection continued to not be possible. In these situations, in order to maintain reliability, the decision was made to forgo the resident's self-report data for that time point.

Care home dynamics. At times, data collection felt like a very challenging experience, as there seemed to be, in some homes, a lack of communication between managers and staff. Staff were not made aware of my visits which, on occasion, led to uncomfortable tensions with other staff members, as they felt unprepared to have a staff member taken off the care floor to meet with me. We tried to overcome this by emphasising to managers that staff must be informed of research visits, and where possible we arranged visits with the staff participants directly. On occasions, though, this was not effective and there was a sense that I was getting in the way, preventing staff from engaging in more important tasks.

This is understandable, in a culture that is so busy and in which staff have so many competing priorities. I also recognised that for a lot of the homes, our project was very alien. Many of the homes had previous involvement with medical clinical trials, which had been a very different, much less labour intensive, process to psychological research. I often wondered whether the researchers for medical interventions came across the same barriers as we had experienced or whether their research was perceived to be a more acceptable by care home staff and management.

My experiences contrasted greatly, however, and in other homes or on other occasions I was seen as part of the staff team. I was spoken to openly about the challenges faced by both care home staff and managers and in turn was able to have conversations about the importance of research even in the presence of such challenges. I was able to build a stronger rapport with the staff in these homes,

which meant that I could communicate directly with staff members and not just rely on managers. This led to fewer delays in recruitment and better planned data collection visits.

#### **Future Research**

One of the main themes that came up during the post intervention staff interviews was the impact of resident factors on programme completion. This issue was raised to Hayward in the original trial and was also discussed during the consultation phase for this study. In response we created an optional module for residents who struggle to engage, but it seems that unfortunately this did not fully resolve the difficulties present when residents wanted to be left alone.

Reflecting back on the qualitative feedback from the consultation phase and the post-intervention data in this study we failed to include a significant perspective: the views of the resident participants. This, admittedly, was not possible during the consultation phase, as the attrition rate of the original study had been so high and the time passed between studies, as previously stated, made it difficult to arrange meetings with formerly recruited care homes. Resident perspectives would, however, have been a valuable source of information at post intervention.

Interviews with residents would have allowed us to learn more about what was helpful in the programme but also more broadly about their experience of relocation and the support they would have liked to receive during this process. All of which could have helped improve our understanding of the needs of residents who seem disengaged. Moving forward, residents should be involved as consultants during programme development stages. It is recognised that preferences will differ between individuals but hopefully working collaboratively with residents, would

help us think of more strategies for supporting them through the different stages of adjustment. This is in line with MRC recommendations which highlight the importance of service user involvement during intervention development, as to ensure that the intervention designed is relevant and therefore helpful (Craig et al., 2008).

# Conclusion

Feasibility testing provides the opportunity to investigate the 'key uncertainties' that are present in an intervention (Craig et al., 2008, pg.8). This paper has examined the feasibility issues and dilemmas present in our study, including recruitment difficulties, organisational barriers and programme factors, affecting programme delivery, data collection and staff acceptability of SettleIN. It is clear that following this pilot study, multiple uncertainties remain and consequently we cannot be certain that the intervention was consistently implemented or adhered to, nor can we make assumptions about recruitment numbers obtainable for future trials. MRC guidelines are clear that these matters would need to be resolved prior to a full scale trial (Craig et al., 2008). This paper has provided ideas about how these issues could be addressed in a further pilot study, which would hopefully pave the way for a large randomised control trial of a much needed intervention.

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# Appendices

# Appendix A

**Jadad Quality Criteria** 

# **Jadad Quality Criteria**

Each question can be answered with a yes or no answer; each yes answer scores one point and each no answer scores zero points.

- 1. Was the study described as randomised?
- An additional point is given if the randomisation method was described and was deemed appropriate.
- A point is deducted if the randomisation method was deemed inappropriate
- 2. Was the study described as double blind?
- An additional point is given if the method of blinding was described, and was deemed appropriate.
- A point is deducted if the method of blinding was deemed inappropriate.
- 3. Was there a description of withdrawals and dropouts? (An article should describe the number of withdrawals and drop-outs, in each of the study groups, and the underlying reasons.

# Appendix B

**Joint Project Contributions Outline** 

# Outline of contributions to the research project

Task	Contributor
Designing the research study	CS and JM
Ethics	CS and JM
Enhancing SettleIN	CS, JM and JH
Recruitment	CS and JM
Baseline data collection	CS
SettleIN training	JM
SettleIN supervision	JM
Week seven data collection	CS
Interviewing staff participants	CS
Data entry	CS and JM

CS= Caroline Saint, JM = Judy Murrill, JH= Janine Hayward

# Appendix C

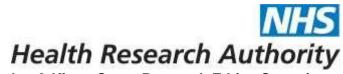
**Consultation Interview Schedule** 

# **Consultation Interview Schedule**

- 1) Does the introduction give you enough information?
- 2) Is the guidance clear enough?
- 3) For each module:
  - a) Are there any activities that don't seem practical/possible to do?
  - b) Are there any activities that you think would be particularly helpful?
  - c) Do you remember any of the activities from the previous trial that worked well?
  - d) Were there any activities that didn't work well or that need adjusting?
- 4) Between 0 (not at all) and 10 (very):
- a) How simple do the forms look to complete?
- b) How easy do you think the manual would be to use?
- c) How helpful do you think each module would be?
- d) How likely is it that you would complete this programme?
- e) Would you be interested in delivering this programme?
- 5) From your experience with SettleIN, are there any differences between this programme and the previous programme in terms of:
  - a) How practical the programme would be to carry out in a busy care home setting?
  - b) How accessible the programme is e.g. simple layout, clear instructions, and clear forms?
  - c) How difficult it would be to complete the activities?
  - d) How useful you think the programme would be?
- 6) Is there anything you think we've missed?

# Appendix D

**Ethics** 



# **London - Camden & Kings Cross Research Ethics Committee**

Jarrow Business Centre Rolling Mill Road Jarrow NE32 3DT

Tel: 0207 104 8087

<u>Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented</u> at NHS sites in England until the outcome of the HRA assessment has been confirmed.

22 February 2017

Judy Murrill

**Trainee Clinical Psychologist** 

University College London

Dear Judy

Study title: An Adjustment to Care Intervention for People with

**Dementia: A Feasibility Pilot Study in Care Homes** 

REC reference: 15/LO/0611

Amendment number: SA1

Amendment date: 12 December 2016

IRAS project ID: 173126

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Summary of amendment

This amendment was submitted to seek approval for the addition of a control group, who would receive care as usual, and would require a larger sample of participants to be recruited of around 30 participants and 30 staff members.

Two additional researchers would be included in the research, Caroline Saint and Judy

Murrill, who would act as lead researchers, and Janine Hayward would now act as an External Supervisor. Furthermore, Clive Ballard would no longer be involved in the research.

A new measure, the Approaches to Dementia Questionnaire, was added for use in the study, which sought to explore staff attitudes towards dementia.

Additionally, training time was reduced from half a day to one hour and fifteen minutes, as the existing length of time was not feasible in a care home setting.

# **Ethical opinion**

The members of the Committee taking part in the review gave a **favourable ethical opinion** of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee did not raise any ethical issues.

# **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
GP/consultant information sheets or letters [GP Information Letter - Highlighted Changes]	0.4	10 December 2016
Notice of Substantial Amendment (non-CTIMP)	SA1	12 December 2016
Other [Site-Specific Agreement Letter - Highlighted Changes]	0.4	11 December 2016
Other [UCL Insurance Registration Form - Highlighted Changes]	15	12 December 2016
Other [UCL Student Study Registration Form - Highlighted Changes]	11	31 January 2017
Other [Letter to Nominated Consultee - Highlighted Changes]	0.4	13 December 2016
Other [Personal Consultee Invitation - Highlighted Changes]	0.4	13 December 2016
Other [Letter to Personal Consultee - Highlighted Changes]	0.4	13 December 2016
Other [Nominated Consultee Invitation - Highlighted Changes]	0.3	13 December 2016
Other [Caroline Saint CV]		
Other [Judy Murrill CV]		
Participant consent form [Nominated Consultee Declaration - Highlighted Changes]	0.3	13 December 2016
Participant consent form [Personal Consultee Declaration - Highlighted Changes]	0.4	13 December 2016
Participant consent form [Resident Participant Assent and Witness Form - Highlighted Changes]	0.6	13 December 2016
Participant consent form [Resident Participant Consent Form - Highlighted Changes]	0.4	13 December 2106
Participant consent form [Care Home Manager Consent Form - Highlighted Changes]	0.3	13 December 2016
Participant consent form [Staff Consent Form - Highlighted Changes]	0.3	13 December 2016
Participant information sheet (PIS) [Care Home Manager Invitation and Information Sheet - Highlighted Changes]	0.6	10 December 2016
Participant information sheet (PIS) [Nominated Consultee Information Sheet - Highlighted Changes]	0.6	10 December 2016
Participant information sheet (PIS) [Personal Consultee Information Sheet - Highlighted Changes]	0.3	11 December 2016
Participant information sheet (PIS) [Resident Participant Information Sheet - Highlighted Changes]	0.5	12 December 2016
Participant information sheet (PIS) [Staff Information Sheet - Highlighted Changes]	0.6	11 December 2016

Research protocol or project proposal [Study Protocol - Highlighted	4.0	12 December 2016
Changes]		
Validated questionnaire [ADQ]	N/A	

# **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

# **Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

15/LO/0611:	Please quote this number on all correspondence	
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Yours sincerely

#### Mrs Rosie Glazebrook Chair

E-mail:

Enclosures: List of names and professions of members who took part in the

review

Copy to: Mr Dave Wilson, UCL

Dr Aimee Spector, Department of Clinical, Educational and Health Psychology, UCL

# Appendix E

# Information sheets and consent forms

Care home manager information sheets and consent form

Resident information sheets and consent forms

Family information sheets and consent form

Staff information sheets and consent form

Nominated Consultee information sheets and consent form

GP information sheet

### Care home manager information sheet and consent form

#### RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London WC1E 6BT General Enquiries Tel: +44 (0)20 7679 1897

Fax: +44 (0)20 7916 1989

http://www.ucl.ac.uk/clinical-psychology/



# SettlelN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study

(Doctoral Student Study)

Version ...0.6........., Date ......10<sup>th</sup> December 2016

# Information for Care Home Manager about the research

You are invited to grant approval for the care home you currently manage to participate in a research project to help develop and test an intervention that aims to, support healthy adjustment to new accommodation for people with dementia, who have recently relocated from independent or family based care. The intervention is based on best practice identified in research to date for supporting relocation based adjustment and minimising negative factors influencing adjustment. It attempts to provide staff and carers with a process tool; a manualised, standardised yet flexible, person centred approach to supporting healthy adjustment in people with dementia. The study will be conducted by Caroline Saint and Judy Murrill as part of their training at University College London and will be submitted as a thesis in partial fulfilment of the requirements for the postgraduate degree of Doctor of Clinical Psychology. Before you decide if you want to join, it's important to understand why the research is being done and what it would involve for you. So please consider this leaflet carefully and ask the researcher any questions you may have.

#### Why are we doing this research?

Research shows that admission into a residential care home for people with dementia (PwD) has been linked with both positive and negative psychological outcomes for both the resident and their carers. Whilst some PwD adjust spontaneously to care home placement (adjustment commonly taking between two to four weeks or as long as six months) many never adjust at all or adjustment is complex and linked to cognitive and behavioural decline. Therefore, support for healthy adjustment is needed. This study is developing and testing a new intervention to help support successful and healthy

adjustment in people with dementia when they relocate from independent or family care into a care home.

The intervention is an easy to use, person centred tool (and manual) that outlines a framework and structure for considering the adjustment needs of newly admitted residents. It covers a range of fifteen positive and negative factors condensed into a small number of modules that are helpful to consider when supporting a person to adapt quickly and successfully to their new home. The tool provides a standardised approach to selecting and implementing components of a tailored adjustment support (settling in) programme for a new resident. The SettleIn tool has been developed with feedback from care home managers, staff, service users, families and carers of people with dementia and professionals working in dementia care.

# Why have I been invited to take part?

You have been invited to join the study because you currently manage one of the care homes that admit people with dementia and are in a position to grant approval for the care home to be denoted as a research site for this project.

#### Do I have to take part?

No: it's up to you. Please read through this information sheet and think carefully about whether you want to take part. We invite you to attend a meeting with a researcher at your workplace about the study. If you have any questions about the study, you can ask the researcher then. If you are willing to take part in the study, we will ask you to sign a consent form to show you have agreed for the care home to take part.

#### What will happen if I take part?

If you were to take part in this study, the residents of your care home (and therefore their assigned key workers) will be randomised into one of two groups; one group receiving the SettleIN intervention, and the other receiving care as usual. This will allow us to make comparisons between the impact of the SettleIN programme and natural adjustment.

If you agree for the care home to be a research site for this project you will be asked to do the following:

- Disseminate information sheets about the study (these will be provided to you) to your staff and make them aware of the opportunity to participate in the study at team meetings.
- 2. Provide support to staff members that wish to participate in the study by approving their attendance to the half-day on-site training and supporting their lead and involvement in intervention delivery.
- 3. Attend the training programme, which will be held at the care home where you work and involve one training workshop of approximately half a day in length.
- 4. Identify potential participants considering the inclusion and exclusion criteria provided (i.e. new admissions of people with dementia) and contact them or ask

a member of the care team to contact the potential participant about the study and seek permission for the researcher to directly contact the potential participant.

- 5. Support the staff participants to be available to complete the measures, to take part in interviews (approximately 30 minutes each) and for those in the SettleIN condition to apply the healthy adjustment intervention and in particular support the assessments needs phase which is anticipated as a 30 minute meeting involving the resident, carer if there is one, direct care team representative and principal researcher. The purpose of the meeting is to assess the adjustment needs of the person with dementia (participant) and identify the intervention programme modules most appropriate for the participant.
- 6. Over the intervention period (currently planned for one month) support staff with and facilitate the completion of the intervention modules with the participant, as relevant (i.e. if the module involves talking with the participant about their move it may involve organising for a psychologist to attend to do this or if the module involves creating a life book it may involve the staff member interviewing the participant and their family to gather information to create a life book and ask the participant and family to contribute photographs. Please note that there is separate guide on how to go about this activity). Activities may range from 30 minutes to one hour. Also remind and support participating staff in the SettleIN group to complete field notes (simple templates will be provided in order to make this no more than a 5 minute task).
- 7. At the end of the intervention we will invite you to discuss your thoughts and ideas about the practicality, feasibility and impact of the intervention. This will involve you taking part in a face-to-face or telephone based interview lasting approximately 30 minutes. If face-to-face, it will be held at the care home where you work and take place within a month of all resident participants completing the intervention.

#### What are the possible benefits of taking part?

The potential benefits for you are improvement of skills and/or knowledge about healthy, positive adjustment and prevention of adverse reactions in residents with dementia. We hope that the intervention will help you to provide the best care possible for your residents, potentially leading to a consistent, standardised yet flexible admission support process, which may enhance their quality of life.

It is also hoped that this study will help us to improve relocation and transitions for people with dementia in general and make staff delivery of effective admission and adjustment support easier for staff, families and residents.

#### What are the risks of taking part?

We do not expect there to be any risks of taking part in this study over and above those that would be part of your normal job. However if being involved in this research really does not suit you, for example if you find it distressing, you are free to withdraw at any point.

Although it is not anticipated that the face-to-face interactions will cause any stress or distress, this is a possibility. If, for any reason you do become distressed the researcher, who is a clinician with appropriate training, will be available to help you manage this in the most appropriate way.

#### What happens if I don't want to carry on with the study?

You can withdraw approval for the care home to be used for the study at any time, without giving a reason. If you choose to withdraw the care home from the study this will not affect your employment in any way.

# Will our taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. It will be shared with associated university researchers who have a duty to you as research participants. However, if you or another member of staff were to disclose issues related to protection of vulnerable adults during the research, we might have to share this information with an appropriate person. We would discuss this with you before we notified anyone else.

# What will happen to the information I give?

One of the requirements for taking part in the study is that you plan to be working at the care home throughout the study (until [date]). If you plan to leave your job before this date and so decide not to take part in the study we will not share this information with your manager.

The results of the research study will be published in a report that will be available to you and your workplace and in journals for medical professionals and other scientists. Your name or the name or your workplace will not appear in any report or publication.

# Who is organising and funding the research?

The research is being organised and funded by the Research Department of Clinical, Educational and Health Psychology, part of University College London.

#### Who has reviewed this study?

The study has been reviewed by UCL Research Department of Clinical, Educational and Health Psychology/ Reviewer Dr Georgina Charlesworth, Clinical Psychologist and specialist in research for people with dementia and family carers of people with dementia. The study has also been reviewed by the Camden and Kings Cross Research Ethics Committee.

#### What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, UCL complaints mechanisms are available to you.

Please report the complaint through

Research Office, UCL, Gower Street, London WC1E 6BT.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. Please make the claim in writing to Dr Aimee Spector who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

### **Contact details**

If you would like to know more, please contact the Researchers, Caroline Saint and Judy Murrill, or the Chief Investigator Dr Aimee Spector, on 020 7679 1897, or by writing to the address on the letterhead.

Thank you for reading this – please ask any questions you may have.

Yours

Caroline Saint Trainee Clinical Psychologist Judy Murrill Trainee Clinical Psychologist

Dr Aimee Spector Senior Lecturer in Clinical Psychology University College London Dr Janine Hayward Chartered Clinical Psychologist External Supervisor

# RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY University College London Gower Street London WC1E 6BT General Enquiries Tel: +44 (0)20 7679 1897 Fax: +44 (0)20 7916 1989 http://www.ucl.ac.uk/clinical-psychology/ Participant identification Number (Office Use Only): Name of Researchers: Judy Murrill and Caroline Saint Title of project: SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study **CONSENT FORM** Please initial box I confirm that I have read and understand the information sheet dated ( for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. 2. I confirm that I have had sufficient time to consider whether the care home I manage and/or I want to be included in the study 3. I understand that my participation is voluntary and that I am free to withdraw the care home and/or my participation at any time, without giving any reason, without my occupational status or legal rights being affected. 4. I understand that data collected during the study may be looked at by members of the research team from University College London or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. 5. I agree to take part in the above study.

Name of Person Date Signature taking consent

Date

Name of Participant

When completed, 1 for care home manager; 1 for researcher as part of the study documentation; 1 (original) for researcher site file

Signature

# Participant information sheet and consent forms

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London WC1E 6BT General Enquiries Tel: +44 (0)20 7679 1897

Fax: +44 (0)20 7916 1989

http://www.ucl.ac.uk/clinical-psychology/



#### PARTICIPANT INFORMATION SHEET

Version	0.6	Date	
V CI 31011		Date	

**Study Title:** SettleIN: Exploring adjustment to care homes for people with memory and/or communication problems (student study).

## Invitation to participate in a research study

You are being invited to take part in a research study. The study will be conducted by Caroline Saint and Judy Murrill, and will form part of a postgraduate degree in Clinical Psychology at University College London.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

#### What is the purpose of the study?

This study is testing out a programme called SettleIN, designed for people with memory and communication problems to adjust and adapt to living in new accommodation. This programme involves helping these people, their carers and staff who look after them, to choose the best activities to support their sense of well being while they become familiar with their new surroundings and make them feel at home.

### Why have I been invited?

You have been invited to take part because you are considered to be experiencing memory problems and/or communication difficulties.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you can change your mind and withdraw at any time without giving a reason. If you decide not to take part, at any time, this will not affect the standard of care you receive.

#### What will happen to me if I take part?

If you decide to take part, you will receive your usual care, or your usual care plus the SettleIN programme. Assignment to the SettleIN programme is random, so there is a 50% chance that you will receive the programme.

A psychologist/researcher will spend time with you to complete short questionnaires to ask about your wellbeing. This will happen on three occasions spread out over two months.

In the SettleIN group, a member of staff and/or your carer will spend time with you to complete specifically designed activities that are tailored to you. The activities may include things like talking about the decision to move and how you feel about it, identifying a goal you would like to achieve or helping you to do an activity you have always done and enjoyed but don't know how to do in your new home.

## What are the possible disadvantages and risks of taking part?

We believe that the risks involved in taking part in the research are minimal. However, you may find some of the talking activities, as part of staff, carers and psychologists supporting your adjustment, upsetting or distressing. If you do find any part of being in the research distressing, you are free to withdraw at any point.

#### What are the possible benefits of taking part?

Hopefully you will find our 3 discussions with you over 10 weeks to be engaging and friendly. We would certainly look forward to having this time with you. If you are in the group that receives the SettleIN programme, we hope that you will find the activities helpful, interesting and fun.

For all participants, the information we get from this study may help us to better support people with memory problems and/or communication difficulties in the future in situations when they relocate to new homes.

# Will my taking part in the study be kept confidential?

All information collected about you will be kept private unless there is a concern about risk; if we are concerned about your or another person's safety we may need to break confidentiality and share any relevant information.

All documents that leave the care home will have your name removed, with the exception of a consent form, which will be kept in a locked cabinet. Once the study has finished University College London will keep the study data in a secure location.

We will ask for your permission to inform your GP about your participation in the study so that they can be up to date in all matters of your care. If you decide not to have your GP informed you may still participate in the study.

# What happens when the study stops?

The workbooks from the SettleIN programme will be available for all participants once the study has finished. This includes those who did not receive the SetteIN programme during the research study. This means that people can access parts of the programme should they want to once the study has finished.

#### What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care you receive. We will need to use all data collected in the study, up to the point of withdrawal.

# What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, UCL complaints mechanisms are available to you. Please report the complaint through at the Joint Research Office, UCL, Gower Street, London WC1E 6BT.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. Please make the claim in writing to Dr Aimee Spector who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

## Who is organising and funding the research?

The research is being organised and funded by University College London. The study will be conducted by Caroline Saint and Judy Murrill, Trainee Clinical Psychologists who are being supervised by Dr. Aimee Spector, who is a Clinical Psychologist.

# What will happen to the results of the research?

The results will be published in journals for health care professionals and other scientists. No-one who takes part will be identified in any publication. Once the study has ended you will be invited to hear the researcher present the study findings at your care home. If you would prefer to have a written report this is also be possible.

#### Who has reviewed the study?

The study has been reviewed by UCL Research Department of Clinical, Educational and Health Psychology / Reviewer Dr Georgina Charlesworth, Clinical Psychologist and specialist in research for people with dementia and family carers of people with dementia. The study has also been reviewed by the Camden and Kings Cross Research Ethics Committee.

## Who can I contact for further information?

For more information about this research, please contact:

Caroline Saint or Judy Murrill

Department of Clinical, Educational and Health Psychology

UCL

Gower S	Street
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WC1E 6BT

# Or if you have any complaints about this study please contact:

Dr Aimee Spector

Department of Clinical, Educational and Health Psychology

UCL

Gower Street

WC1E 6BT

# Thank you for thinking about taking part in this research study

Yours

Caroline Saint

Trainee Clinical Psychologist

Judy Murrill

Trainee Clinical Psychologist

Dr Aimee Spector

Senior Lecturer in Clinical Psychology

University College London

Dr Janine Hayward

**Chartered Clinical Psychologist** 

**External Supervisor** 

#### RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London WC1E 6BT General Enquiries Tel: +44 (0)20 7679 1897

Fax: +44 (0)20 7916 1989

http://www.ucl.ac.uk/clinical-psychology/



# PARTICIPANT CONSENT FORM

**Study Title:** SettleIN: Exploring adjustment to care homes for people with memory and/or communication problems. An intervention development and feasibility pilot (student study).

Name of Researchers: Caroline Saint and Judy Murrill

Participant Number:

Please initial boxes

I. I confirm that I have read and understand the information sheet dated [ ], version [] for the above study and have had the opportunity to ask questions and have had these answered acceptably.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes (including my Medication Administration Records) and data collected during the study, may be looked at by individuals from University College London or from regulatory authorities- where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records.	
4. I understand that all information given by me or about me will be treated as confidential by the research team.	
5. I understand my GP will be informed of my participation in this study unless 'Do not Inform' is indicated here	Circle if preferred:

			DO NOT INFORM GP
6. I agree to take p	part in the above study.		
Name of participant	Date	Signature	
Name of person taking consent (if different from the principal researcher)	Date	Signature	
Principal researcher	Date	Signature	

When completed, 1 for resident (file at site); 1 for researcher as part of the study documentation; 1 (original) for researcher site file

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#### PARTICIPANT ASSENT AND WITNESS FORM

Version .	0.6	Date	

**Study Title:** SettleIN: Exploring adjustment to care homes for people with memory and/or communication problems. An intervention development and feasibility pilot (student study).

## Invitation to participate in a research study

You are being invited to take part in a research study.

#### What is the purpose of the study?

This study is testing out a programme called SettleIN, designed for people with memory and communication problems to adjust and adapt to living in new accommodation. This programme involves helping these people, their carers and staff who look after them, to choose the best activities to support their sense of wellbeing while they become familiar with their new surroundings and make them a feel at home.

#### What will happen if I take part?

If you decide to take part, you will receive your usual care, or your usual care plus the SettleIN programme. Assignment to the SettleIN programme is random, so there is a 50% chance that you will receive the programme.

A psychologist/researcher will spend time with you to complete short questionnaires to ask about your wellbeing. This will happen on three occasions spread out over two months.

In the SettleIN group, a member of staff and/or your carer will spend time with you to complete specifically designed activities that are tailored to you. The activities may include things like talking about the decision to move and how you feel about it, identifying a goal you would like to achieve or helping you to do an activity you have always done and enjoyed but don't know how to do in your new home.

A researcher will also speak to a member of staff who knows you well and look through your medical notes to get information about you and your care.

#### Do I have to take part?

You do not have to take part in this study. If you do decide to take part you will be free to stop the study at any time, without giving a reason. Stopping the study will not affect the care you receive.

#### Will my taking part in the study be kept confidential?

The researcher will not tell other people (i.e. people not involved in your care) that you are taking part in the study or share any information about you unless we are concerned about your or another person's safety. We will keep some written information about you but this will be kept securely. We will ask for your permission to inform your GP about your participation in the study so that they can be up to date in all matters of your care. If you decide not to have your GP informed you may still participate in the study.

# What if there is a problem?

If you wish to complain, or have an	ny concerns about any	$\prime$ aspect of the way you have
been approached or treated by men	nbers of staff you may	have experienced due to your
participation in the research, UCL of	omplaints mechanism	s are available to you. Please
report the complaint through		at the Joint Research Office,
UCL, Gower Street, London WC1E	6BT.	

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. Please make the claim in writing to Dr Aimee Spector who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

#### If you sign below;

If you sign below, this means that you have read this form, or have had it read to you, and that you are willing to be in this study. A researcher will then speak to someone who will think about your best interests and advise whether they think it is ok for you to take part in this study.

Name of Participant	Date	Signature	
Consent to Inform GP	Granted / Not Gran	ted (please cross out or	ne)

Name of person who has	Date	Signature
discussed the study and		
provided me with		
information		

If you are unable to sign your name, a member of staff can witness you telling the researcher that you are willing to be in this study.

Name of staff member witness	Date	I have witnessed that the participant has told the researcher they are willing to be in this study
		Signature to confirm the above

You will keep a copy of this form. One copy with also be kept in your care records and one copy will be kept by the researcher.

# Family member information sheet and consent form

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

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# INVITATION TO ACT AS PERSONAL CONSULTEE

**Study Title:** SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study (Doctoral Student Study)

Patient Number:

Researcher: Caroline Saint and Judy Murrill

I agree with this statement
Signed
I agree to being contacted further about the study  Signed
I do not agree to being contacted further about the study  Signed

#### **Contact details:**

Name:

Contact number:

Most convenient time(s) to be contacted:

Thank you for completing the form. Please return it in the stamped addressed envelope or leave it F.A.O Caroline Saint/ Judy Murrill at care home.

#### RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London WC1E 6BT General Enquiries Tel: +44 (0)20 7679 1897

Fax: +44 (0)20 7916 1989

http://www.ucl.ac.uk/clinical-psychology/



Study Title: SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study

# PERSONAL CONSULTEE INFORMATION SHEET

Version	0.6	Date	

#### Introduction

We feel your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend (though their information sheets refer to 'memory problems and/or communication difficulties rather than dementia).

**Study Title**: SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study

# What is the purpose of the study?

Research shows that admission into a residential care home for people with dementia (PwD) has been linked with both positive (e.g. Bekhet et al, 2008) and negative psychological outcomes for both the resident and their carers (Sury, Burns & Brodaty, 2013). Whilst some PwD adjust spontaneously to care home placement (adjustment commonly taking between two to four weeks or as long as six months (Ellis 2010; Hodgson et al, 2004) many never adjust at all or adjustment is complex and linked to cognitive and behavioural decline (e.g. Kydd 2001; Wilson et al, 2007). Therefore, support for healthy adjustment is needed. This study is developing and testing a new intervention to help support successful and healthy adjustment in people with dementia when they relocate from independent or family care into a care home.

The project has been approved by the Camden and Kings Cross Research Ethics Committee. We shall make sure that the project is safe for each participant and does not cause them undue distress. To help with this, the researchers need information from people who have known the participant for some time or those who have agreed to be consulted on such matters.

#### Why have I been contacted?

We are intending to recruit participants to this project who may not have the capacity to consent to their participation. This means that they may not be able to judge for themselves whether they would like to take part or refuse. The project includes such participants because we are studying the impact of an intervention for people with dementia, an illness which limits a person's ability to give consent.

If you do know the prospective participant, you may be able to advise us about any possible difficulties they may have in taking part. You also may be able to tell us how they may communicate that they wanted to cease being involved with the project.

To help decide if the prospective participant should join the study, we'd like to ask your opinion whether or not they would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

When thinking about the wishes and interests of the prospective participant, it is important that you should set aside any of your own views about the project.

#### What is required of each participant?

Participants of the study will be randomised into one of two groups; one group receiving a SettlelN intervention, designed to promote healthy adjustment, the other group will receive care as usual. This will allow us to make comparisons between the impact of the SettlelN programme and natural adjustment.

The SettleIN intervention provided in this study directly involves dementia care staff, carers and residents of care homes so that a wide range of views can be gathered regarding the feasibility of the intervention and whether a positive impact on adjustment

was indicated. In order to explore adjustment in all participating residents, we would do the following:

- 1) The principal researcher will look at all participant's medical records to obtain details about any relevant diagnoses, medication, health complexities and preadmission care planning.
- 2) Residents (and/or their carer) and staff will be asked to complete standardised and individualised goal oriented assessments before and after the intervention and at one month following the completion of the intervention. Assessments will take no more than 1.5 hours and be predominantly completed with the carer or staff member.

This will help the researchers to assess whether any impact on healthy adjustment has occurred over time and whether the intervention was practical and feasible to deliver.

Taking part in the study does not involve any lifestyle restrictions. Participants will carry on with their everyday activities as normal though may be offered additional tailored activities while participating in the study.

#### What are the possible disadvantages and risks of taking part?

As support for adjustment to care should be carried out as part of routine relocation to a care home the risk is seen to be minimal and equivalent to that encountered as part of daily care. However if participants find observations significantly distressing they may be withdrawn from the study. A decision to withdraw will be made where the participation is no longer judged to be in the person's best interests. Decisions will be made by the principal researcher through discussion with the Chief Investigator and the person's direct care team. We will need to use all data collected in the study, up to the point of withdrawal.

We will keep you fully informed during the study so you can let us know if you have any concerns or you think that the participant should be withdrawn.

# What are the possible benefits of taking part?

Each participating resident will receive three one to one interactions with a researcher for up to 30 minutes each over a period of 10 weeks. We aim for these interactions to be stimulating and engaging discussions for the resident in which they talk about their life and in which we complete the questionnaires. There is also a 50% chance that each participating resident will receive a programme designed to support adjustment to residential living. Previous research has found that when patients with dementia receive person centred adjustment support, adverse reactions to relocation are prevented and patients can thrive in care home settings.

We hope that research of this kind will result in improved dementia care, particularly at the adjustment phase of relocation. There is a lack of evidence-based intervention for this phase of care for people with dementia i.e. post independent living and before end of life care in dementia; therefore this study may also lead to changes in the way that care is provided in this population.

# Who is organising and funding the research?

The research is being organised and funded by the Research Department of Clinical, Educational and Health Psychology, part of University College London. This project will be submitted by the researcher as a thesis in partial fulfilment of the requirements for the postgraduate degree of Doctor of Clinical Psychology.

#### Who has reviewed the study?

The study has been reviewed by UCL Research Department of Clinical, Educational and Health Psychology / Reviewer Dr Georgina Charlesworth, Clinical Psychologist and specialist in research for people with dementia and family carers of people with dementia. The study has also been reviewed by the Camden and Kings Cross Research Ethics Committee.

# Will participant's information be kept confidential?

All information collected about participants over the course of the study will be kept private unless there is a concern about risk. All documents that leave the care home will have participant's name removed with the exception of a consent form. This form will be kept securely. After the study has finished study data will be kept by UCL in a secure location.

No participants will be identified in any publication arising from the study. The results of the research study will be published in a report that will be available to you and in journals for medical professionals and other scientists. Your name or the name or your workplace will not appear in any report or publication. The researchers will also present the study findings to staff and interested parties at each care home. You are welcome to attend this presentation.

All participants will be asked to grant consent for their GP to be advised that they are participating in the study so that their GP can remain up to date with all matters to do with their care.

#### Will information that I give be kept confidential?

Information about yourself (name, address and telephone number) will be held by the Care organisation. Information that you disclose about the prospective participant will be held by the researcher.

#### What do I have to do now?

If you think that the prospective participant would be interested and you are able to discuss this with the researchers, please fill in the attached 'Invitation to Act as Personal Consultee' form and include your name, contact number and a convenient time when the researchers can contact you. We would be grateful if you could return the 'Invitation to Act as Personal Consultee' within two weeks of the date of our letter. Please also retain the 'Personal Consultee Declaration' form and the spare stamped addressed envelope as we may ask you to complete this once you have spoken to the researchers.

If you think that the prospective participant would be interested but you are not sure about whether you would like to talk about this with the researchers, then please suggest who else could be approached.

If you think that the prospective participant would **not** be interested in taking part, then it is important that you still complete the accompanying form entitled 'Invitation to Act as Personal Consultee'. A stamped addressed envelope is provided. We would be grateful if you could return the 'Invitation to Act as Personal Consultee' form no later than two weeks from the date of our letter.

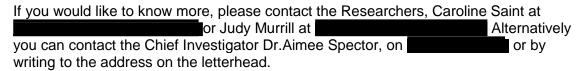
# What if there is a problem?

you wish to complain, or have any concerns about any aspect of the way you have			
been approached or treated by members of staff you may have experienced due to			
our participation in the research, UCL complaints mechar	nisms are available to you.		
Please report the complaint through	at the Joint		
Research Office, UCL, Gower Street, London WC1E 6BT.			

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. Please make the claim in writing to Dr Aimee Spector who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

# For more information about this research, please contact:



If you are unsure about taking the role of consultee and would like seek advice from an independent person who is not associated with the project, please contact:

Dr Chris Barker
Department of Clinical, Educational and Health Psychology
UCL
Gower Street
WC1E 6BT
Email:

# Thank you for thinking about helping us with this research study

Caroline Saint Judy Murrill
Researcher/Trainee Clinical Psychologist Researcher/Trainee Clinical
Psychologist

Dr Aimee Spector Chief Investigator/Senior Lecturer in Clinical Psychology, University College London

Dr Janine Hayward

Chartered Clinical Psychologist

External Supervisor

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## PERSONAL CONSULTEE DECLARATION

**Study Title:** SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study (Doctoral Student Study)

Patient Number:

Researchers: Caroline Saint and Judy Murrill

### Please initial

1.	I confirm that I have read and understood the Information for Personal Consultees (version,	
	dated ) for the study	
2.	I confirm that I have had time and opportunity to	
	ask questions about the study or my role as a Personal Consultee	
3.	I understand the purpose of the project and what	
	the participant's (my partner, friend or relative's) involvement would be. In my opinion, they would	
	not object to taking part in the study	
4.	I understand that participation in the project is	
	voluntary and that the participant would be	
	withdrawn if they do not wish to continue participating and the participant would not have	
	to give a reason.	
5.	I understand that if the participant were	
	withdrawn from the project, this would not affect	
	in any way the care or treatment they receive, or affect their legal rights.	
6.	Please also indicate if in your opinion, the	Please circle one
	participant would consent to inform their GP of their participation in the study. If consent is not	option:
	granted, the GP will not be informed however the	
	participant may still be involved in the study.	Inform GP / Do
		not Inform GP

Name of Consultee	Date	Signature
Name of person who has discussed the study and provided me with information (usually principal researcher)	Date	Signature
Principal Researcher	Date	Signature

Please complete *both* copies of this form and keep one for yourself. Please send the other copy in the stamped addressed envelope provided, thank you.

#### Staff information sheets and consent forms

#### RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

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# SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study

(Doctoral Student Study)

#### Information for staff about the research

Version <b>0.7</b> , Date	Version	0.7	, Date	
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You are invited to participate in a research project to help develop and test an intervention that aims to support healthy adjustment to new accommodation for people with dementia who have recently relocated from independent or family based care. The intervention is based on best practice identified in research to date for supporting positive adjustment and minimising negative factors influencing adjustment. It attempts to provide staff and carers with a process tool; a manualised, standardised yet flexible, person centred approach to supporting healthy adjustment in people with dementia. The study will be conducted by Caroline Saint and Judy Murrill, as part of their training at University College London and will be submitted as a thesis in partial fulfilment of the requirements for the postgraduate degree of Doctor of Clinical Psychology. Before you decide if you want to join, it's important to understand why the research is being done and what it would involve for you. So please consider this leaflet carefully and ask the researchers any questions you may have.

### Why are we doing this research?

Research shows that admission into a residential care home for people with dementia (PwD) has been linked with both positive and negative psychological outcomes for both the resident and their carers. Whilst some PwD adjust spontaneously to care home placement (adjustment commonly taking between two to four weeks or as long as six months) many never adjust at all or adjustment is complex and linked to cognitive and behavioural decline. Therefore, support for healthy adjustment is needed. This study is developing and testing a new intervention to help support successful and healthy adjustment in people with dementia when they relocate from independent or family care into a care home.

#### Why have I been invited to take part?

You have been invited to join the study because you currently work at one of the care homes that have agreed to take part. Your manager has given permission for you to attend the training and to take part in other activities related to the research if you choose to do so.

#### Do I have to take part?

No: it's up to you. Please read through this information sheet and think carefully about whether you want to take part. We invite you to attend a meeting with a researcher at your workplace about the study. If you have any questions about the study, you can ask the researcher then. If you are willing to take part in the study, we will ask you to sign a consent form to show you have agreed to take part.

If you decide that you do not want to take part or you decide to withdraw from the study you do not have to tell us why, and any reason you do give will not be shared with your manager.

### What will happen if I take part?

As a key worker for a resident participating in this study, you will be randomised into one of two groups. One group will be asked to deliver the SettleIN programme, with your manager's support. The other group will provide care as usual. This means that, depending on the group the resident you support is assigned to, you will be assigned to either the SettleIN group or the care as usual group.

If you agree to take part you will be asked to do the following, regardless of the group you are assigned to:

- Complete some questionnaires about yourself (demographic information, qualifications, job details etc.) and your knowledge and attitudes towards dementia. These will take approximately 15 minutes and will be paper and pen based.
- Complete some questionnaires about the participant/s you are caring for and who
  are involved in the research (demographic information, goal attainment, mood,
  adjustment). These will take approximately 20-70 minutes (considerably less,
  depending on availability of relevant family carer) and will be paper and pen
  based.

If you agree to take part and you are assigned to the SettleIN group you will also be asked to do the following:

3. Attend the one to one training programme, which will be held at the care home where you work and will be approximately 1 hour and 15 minutes long. You may also be asked to attend one or two group supervision sessions of approximately an hour, to support you in applying what was learned at the workshop to your clinical work with patients.

There will not be any test or quiz at the end of the training programme.

- 4. Apply the adjustment tool; with colleagues and/or the researcher assess the adjustment needs of the person with dementia (participant) and identify the intervention programme modules most appropriate for the participant. Each assessment should take a maximum of 30 minutes to complete.
- 5. Over the intervention period (currently planned for one month) complete and / or facilitate the completion of the intervention modules with the participant as relevant (i.e. if the module involves talking with the participant about their move it may involve organising for a psychologist to attend to do this or if the module involves creating a life book it may involve the staff member interviewing the participant and their family to gather information to create a life book and ask the participant and family to contribute photographs. Please note that there is separate guide on how to go about this activity). Activities may range from 30 minutes to one hour.
- 6. Complete field notes (using quick, simple templates that are provided) to provide information about what was done and how practical and feasible it was to do it, and it's impact. This is expected to take no more than 5 minutes.
- 7. At the end of the intervention we will invite you to discuss your thoughts and ideas about the practicality, feasibility and impact of the intervention. This will involve you taking part in a face-to-face or telephone based interview lasting approximately 30 minutes. If face-to-face it will be held at the care home where you work and take place within a month of completing the intervention.

### What are the possible benefits of taking part?

All participating staff will receive experience of participating in research and a certificate to add to their employment portfolio.

There is a 50% chance that you will be allocated to the SettleIN group. We hope that engaging in the SettleIN intervention, will mean that those within this group could potentially benefit from an improvement of skills and/or knowledge about healthy, positive adjustment and prevention of adverse reactions in patients with dementia. We hope that the intervention will help staff provide the best care possible for their patients, potentially leading to a consistent, standardised yet flexible admission support process, which may enhance their quality of life.

It is also hoped that this study will help us to improve relocation and transitions for people with dementia in general and make staff delivery of effective admission and adjustment support easier for staff, families and patients.

#### What are the risks of taking part?

We do not expect there to be any risks of taking part in this study over and above those which would be part of your normal job. However if being involved in this research really does not suit you, for example if you find it distressing, you are free to withdraw at any point.

Although it is not anticipated that the questionnaires or face-to-face will cause any stress or distress, this is a possibility. If, for any reason you do become distressed the researcher, who is

a clinician with appropriate training, will be available to help you manage this in the most appropriate way (i.e. accompanying you to a private room).

Participating in the research involves a time commitment and you may experience some minimal inconvenience from attending training and answering questionnaire/completing observational measures. As a small token of appreciation for the time and effort involved in taking part we will provide you with a £10 high-street shopping voucher.

### What happens if I don't want to carry on with the study?

You can withdraw from the study at any time, without giving a reason. If you choose to withdraw from the study this will not affect your employment in any way.

#### Will our taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. It will be shared with associated university researchers who have a duty to you as research participants. However, if you or another member of staff were to disclose issues related to protection of vulnerable adults during the research, we might have to share this information with an appropriate person. We would discuss this with you before we notified anyone else.

We will let your manager know that you are taking part in the study so that s/he can authorise your attendance at the training days and provide any other time away from your clinical duties as needed.

#### What will happen to the information I give?

One of the requirements for taking part in the study is that you plan to be working at the care home throughout the study (until [ ]). If you plan to leave your job before this date and so decide not to take part in the study we will not share this information with your manager.

The results of the research study will be published in a report that will be available to you and your workplace and in journals for medical professionals and other scientists. Your name or the name or your workplace will not appear in any report or publication.

### Who is organising and funding the research?

The research is being organised and funded by the Research Department of Clinical, Educational and Health Psychology, part of University College London.

#### Who has reviewed this study?

The study has been reviewed by UCL Research Department of Clinical, Educational and Health Psychology / Reviewer Dr Georgina Charlesworth, Clinical Psychologist and specialist in

research for people with dementia and family carers of people with dementia. The study has also been reviewed by the Camden and Kings Cross Research Ethics Committee.

University College London

what if there is a problem:	
approached or treated by members of s	taff you may have experienced due to your laints mechanisms are available to you. Please report at the Joint Research Office, UCL, Gower
In the unlikely event that you are harme available.	ed by taking part in this study, compensation may be
hospital's negligence then you may be a writing to Dr Aimee Spector who is the O University College London. The Chief Inv	t of the Sponsor's (University College London) or the ble to claim compensation. Please make the claim in Chief Investigator for the research and is based at vestigator will then pass the claim to the Sponsor's ay have to bear the costs of the legal action initially, this.
Contact details	
If you would like to know more, please or the Chief Investigator Dr. Aimee Specthe letterhead.	contact the Researchers, Caroline Saint and Judy Murrill stor, on to by writing to the address on
Thank you for reading this – please ask	any questions you may have.
Yours	
Caroline Saint	Judy Murrill
Trainee Clinical Psychologist	Trainee Clinical Psychologist
Dr Aimee Spector	Dr Janine Hayward
Senior Lecturer in Clinical Psychology	Chartered Clinical Psychologist

**External Supervisor** 

## RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY University College London Gower Street London WC1E 6BT General Enquiries Tel: +44 (0)20 7679 1897 Fax: +44 (0)20 7916 1989 http://www.ucl.ac.uk/clinical-psychology/ Participant identification Number: Name of Researcher: Title of project: SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study CONSENT FORM Please initial box 1. I confirm that I have read and understand the information sheet dated ......... (version 0.6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. 2. I confirm that I have had sufficient time to consider whether or not want to be included in the study 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my occupational status or legal rights being affected. 4. I understand that data collected during the study may be looked at by members of the research team from University College London or from regulatory authorities-where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. 5. I agree to take part in the above study. Name of Participant Date Signature

taking consent

Name of Person

Date

When completed, 1 for staff member; 1 for researcher as part of the study documentation; 1 (original) for researcher site file

Signature

## Nominated Consultee information and consent forms

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London WC1E 6BT

General Enquiries Tel: +44 (0)20 7679 1897

Fax: +44 (0)20 7916 1989

http://www.ucl.ac.uk/clinical-psychology/



## INVITATION TO ACT AS NOMINATED CONSULTEE

**Study Title:** SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study (Doctoral Student Study)

Patient Number:

Researchers: Caroline Saint and Judy Murrill

I think that the prospective participant may  NOT like to take part in the project.	I agree with this statement
	Signed
I think that the prospective participant may be interested in taking part and I would like to discuss this with the researcher. I have provided a contact number at the times I can be contacted below.	I agree to being contacted further about the study  Signed
I think that the prospective participant may like to take part in the project – but I do not wish to be consulted. I have provided information about an alternative contact person below (if possible).	I do not agree to being contacted further about the study  Signed

### **Contact details:**

Name:

Contact number:

Most convenient time(s) to be contacted:

Thank you for completing the form. Please return it in the stamped addressed envelope or leave it F.A.O Caroline Saint or Judy Murrill at care home.

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### NOMINATED CONSULTEE INFORMATION SHEET

Version ...0.6........., Date ......[to be entered]............

Study Title: SettleIN: Exploring adjustment to care homes for people with

dementia: A feasibility pilot study

### What is the purpose of the study?

Research shows that admission into a residential care home for people with dementia (PwD) has been linked with both positive (e.g. Bekhet et al, 2008) and negative psychological outcomes for both the resident and their carers (Sury, Burns & Brodaty, 2013). Whilst some PwD adjust spontaneously to care home placement (adjustment commonly taking between two to four weeks or as long as six months (Ellis 2010; Hodgson et al, 2004) many never adjust at all or adjustment is complex and linked to cognitive and behavioural decline (e.g. Kydd 2001; Wilson et al, 2007). Therefore, support for healthy adjustment is needed. This study is developing and testing a new intervention to help support successful and healthy adjustment in people with dementia when they relocate from independent or family care into a care home.

The project has been approved by Camden and Kings Cross Research Ethics Committee. We shall make sure that the project is safe for each participant and does not cause them undue distress. To help with this, the researchers need information from people who have known the participant for some time or those who have agreed to be consulted on such matters.

## Why have I been contacted?

We are intending to recruit participants to this project who may not have the capacity to consent to their participation. This means that they may not be able to judge for themselves whether they would like to take part or refuse. The project includes such participants because we are studying the impact of an intervention for people with dementia, an illness which limits a person's ability to give consent.

If you do know the prospective participant, you may be able to advise us about any possible difficulties they may have in taking part. You also may be able to tell us how they may communicate that they wanted to cease being involved with the project.

To help decide if the prospective participant should join the study, we'd like to ask your opinion whether or not they would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

When thinking about the wishes and interests of the prospective participant, it is important that you should set aside any of your own views about the project.

## What is required of each participant?

Participants of the study will be randomised into one of two groups; one group receiving a SettleIN intervention, designed to promote healthy adjustment, the other group will receive care as usual. This will allow us to make comparisons between the impact of the SettleIN programme and natural adjustment.

The SettleIN intervention provided in this study directly involves dementia care staff, carers and residents of care homes so that a wide range of views can be gathered regarding the feasibility of the intervention and whether a positive impact on adjustment was indicated. In order to explore adjustment in all participating residents, we would do the following:

- 1) The principal researcher will look at all participant's medical records to obtain details about any relevant diagnoses, medication, health complexities and preadmission care planning.
- 2) Residents (and/or their carer) and staff will be asked to complete standardised and individualised goal oriented assessments before and after the intervention and at one month following the completion of the intervention. Assessments will take no more than 1.5 hours and be predominantly completed with the carer or staff member.

This will help the researchers to assess whether any impact on healthy adjustment has occurred over time and whether the intervention was practical and feasible to deliver.

Taking part in the study does not involve any lifestyle restrictions. Participants will carry on with their everyday activities as normal though may be offered additional tailored activities while participating in the study.

## What are the possible disadvantages and risks of taking part?

As support for adjustment to care should be carried out as part of routine relocation to a care home the risk is seen to be minimal and equivalent to that encountered as part of daily care. However if participants find observations significantly distressing they may be withdrawn from the study. A decision to withdraw will be made where the participation is no longer judged to be in the person's best interests. Decisions will be made by the principal researcher through discussion with the Chief Investigator and the person's direct care team. We will need to use all data collected in the study, up to the point of withdrawal.

We will keep you fully informed during the study so you can let us know if you have any concerns or you think that the participant should be withdrawn.

### What are the possible benefits of taking part?

We hope that research of this kind will result in improved dementia care, particularly at the adjustment phase of relocation. There is a lack of evidence-based intervention for this phase of care for people with dementia i.e. post independent living and before end of life care in dementia; therefore this study may also lead to changes in the way that care is provided in this population.

There is a 50% chance that each participating resident will receive a programme designed to support adjustment to residential living. Previous research has found that when patients with dementia receive person centred adjustment support, adverse reactions to relocation are prevented and patients can thrive in care home settings.

## Who is organising and funding the research?

The research is being organised and funded by the Research Department of Clinical, Educational and Health Psychology, part of University College London. This project will be submitted by the researcher as a thesis in partial fulfilment of the requirements for the postgraduate degree of Doctor of Clinical Psychology.

### Who has reviewed the study?

The study has been reviewed by UCL Research Department of Clinical, Educational and Health Psychology / Reviewer Dr Georgina Charlesworth, Clinical Psychologist and specialist in research for people with dementia and family carers of people with dementia. The study has also been reviewed by the Camden and Kings Cross Research Ethics Committee.

### Will participant's information be kept confidential?

All information collected about participants over the course of the study will be kept private unless there is a concern about risk. All documents that leave the care home will have participant's name removed with the exception of a consent form. This form will be kept securely. After the study has finished study data will be kept by UCL in a secure location.

No participants will be identified in any publication arising from the study. The results of the research study will be published in a report that will be available to you and in journals for medical professionals and other scientists. Your name or the name or your workplace will not appear in any report or publication. The researchers will also present the study findings to staff and interested parties at each care home. You are welcome to attend this presentation.

### Will information that I give be kept confidential?

Information about yourself (name, address and telephone number) will be held by the Care organisation. Information that you disclose about the prospective participant will be held by the researcher.

#### What do I have to do now?

If you think that the prospective participant would be interested and you are able to discuss this with the researchers, please fill in the attached 'Invitation to Act as Nominated Consultee' form and include your name, contact number and a convenient time when the researcher can contact you. We would be grateful if you could return the 'Invitation to Act as Nominated Consultee' within two weeks of the date of our letter. Please also retain the 'Nominated Consultee Declaration' form and the spare stamped addressed envelope as we may ask you to complete this once you have spoken to the researchers.

If you think that the prospective participant would be interested but you are not sure about whether you would like to talk about this with the researchers, then please suggest who else could be approached.

If you think that the prospective participant would **not** be interested in taking part, then it is important that you still complete the accompanying form entitled 'Invitation to Act as Nominated Consultee'. A stamped addressed envelope is provided. We would be grateful if you could return the 'Invitation to Act as Nominated Consultee' form no later than two weeks from the date of our letter.

### What if there is a problem?

If you wish to complain, or have any $\mathfrak q$	concerns about any aspect of	the way you have
been approached or treated by mem	bers of staff you may have ex	perienced due to
your participation in the research, UC	CL complaints mechanisms are	e available to you.
Please report the complaint through		at the Joint
Research Office, UCL, Gower Street	, London WC1E 6BT. Telepho	one:

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. Please make the claim in writing to Dr Aimee Spector who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

### For more information about this research, please contact:

lf	you	would	like	to	know	more,	please	contact	the	Researcher,	Caroline	Saint	at
						or Ju	dy Murr	ill at			Alt	ernative	ely
yc	u ca	n conta	ct the	e C	hief Inv	estigat	tor Dr.Ai	mee Spe	ector	, on	, or	by writi	ng
to	the a	address	s on t	the	letterh	ead							

If you are unsure about taking the role of consultee and would like seek advice from an independent person who is not associated with the project, please contact:

Dr Chris Barker



## Thank you for thinking about helping us with this research study

Caroline Saint Researcher/Trainee Clinical Psychologist Psychologist Judy Murrill Researcher/Trainee Clinical

Dr Aimee Spector Senior Lecturer in Clinical Psychology University College London Dr Janine Hayward Chartered Clinical Psychologist External Supervisor

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## NOMINATED CONSULTEE DECLARATION

Study Title: SettlelN: Exploring adjustment to care homes for people with dementia: A feasibility pilot study (Doctoral Student Study)

Patient Number:

Researchers: Caroline Saint and Judy Murrill

### Please initial

I. I confirm that I have read and understood the Information for Nominated Consultees (version 0.4, dated ) for the study	
2. I confirm that I have had time and opportunity to ask questions about the study or my role as a Nominated Consultee	
3. I understand the purpose of the project and what the participant's involvement would be. In my opinion, they would not object to taking part in the study.	
4. I understand that participation in the project is voluntary and that the participant would be withdrawn if they do not wish to continue participating and the participant would not have to give a reason.	
5. I understand that if the participant were to withdrawn from the project, this would not affect in any way the care or treatment they receive, or affect their legal rights.	
6. Please also indicate if in your opinion, the participant would consent to inform their GP of their participation in the study. If consent is not granted, the GP will not be informed however the participant may still be involved in the study.	Please circle one option:
	Inform GP / Do not Inform GP

Name of Consultee	Date	Signature
Name of person who has discussed the study and provided me with information (usually principal researcher)	Date	Signature
Principal Researcher	Date	Signature

Please keep a copy of this form for yourself. Please send the original copy in the stamped addressed envelope provided, thank you.



Department of Clinical, Educational and Health Psychology
University College London
Gower Street
London
WC1E 6BT
Phone:

#### **GENERAL PRACTITIONER INFORMATION SHEET**

**Study Title**: SettleIN: Exploring adjustment to care homes for people with dementia. A feasibility pilot study (Doctoral Student Study)

Your patient, [ ], is taking part in a research study. Please find enclosed a copy of the 'Participant Information Sheet', which they have received.

The study will be conducted by Caroline Saint and Judy Murrill, Trainee Clinical Psychologists, as part of their training at University College London. They are being supervised by Dr. Aimee Spector, academic staff member at University College London and Professor Clive Ballard, academic staff at Kings College London, both of whom are Clinical Psychologists.

This study is a pilot of a new intervention designed to support healthy adjustment of people with dementia who relocate from independent or family supported living into a care home.

Participants of the study will be randomised into one of two groups; one group receiving a SettleIN intervention, designed to promote healthy adjustment, the other group will receive care as usual. This will allow us to make comparisons between the impact of the SettleIN programme and natural adjustment.

The SettleIN intervention is for the residents of care homes and will involve staff and/or carers facilitation of activities within the intervention programme collaboratively with the resident. In order to study the effects of the intervention on adjustment, the following will be undertaken:

- The principal researcher will look at all participants' medical records to obtain details about any relevant diagnoses, medication, health complexities and preadmission care planning.
- 2) All residents (or their carer) and participating staff will be asked to complete standardised and individualised goal oriented assessments before and after the intervention and at one month following the completion of the intervention.

This will help the researchers to assess whether any impact on healthy adjustment has occurred over time and whether the intervention was practical and feasible to deliver.

Taking part in the study does not involve any lifestyle restrictions. Participants will carry on with their everyday activities as normal though may be offered additional tailored activities while participating in the study.

The study will **not** affect your patient's current or future treatment.

The results of this study are expected to be published in relevant journals. The information collected in the study will be anonymous and patients will not be identified in any report/publication. All information is confidential and will not be disclosed to anyone else unless there is a concern about risk to the participant or someone around them. If this is the case the researcher will discuss their concerns with the participant's care team.

The local Ethics Committee reviews all proposals for research using human subjects before they can proceed. The Camden and Kings Cross Research Ethics Committee has granted the appropriate permission for this study.

Thank you for reading this information sheet. Please do not hesitate to contact me at the above address or email if you feel there is anything that is not clear, or if you would like more information.

Kind regards

Caroline Saint

Judy Murrill

Trainee Clinical Psychologist Psychologist

Trainee Clinical

## Appendix F

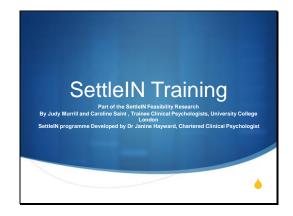
## The SettleIN Programme

SettleIN training slides

SettleIN training handouts

## **SettleIN training slides**

## Slide 1



## Slide 2



## Slide 3

## What is SettleIN?

Comes in the form of 2 manualswhich we will look at today.

- A programme for care home staff to help new residents with dementia, quickly and successfully adjust to their new home
- Manualised programme
- ♦ Aims to promote healthy, positive adjustment

#### Slide 4

## SettleIN Research

- Your Care Home is trialling SettleIN which is part of a Major Research Project at University College London
- HOW THE RESEARCH WORKS

  Residents will be randomly allocated to the SettleN group (molves care staff and new residents receive the standard care from care staff in their new care home).

  Before starting the programme we complete questionnaires with the resident, you, and if possible the resident's family.

- possible the resident's family
  You run Settliel
  We repeat the questionnaires at the end of four weeks once Settlelin is finished
  We repeat the questionnaires again four weeks later
  We interview you (a 30 minute chat) about how easy (or not!) Settlel'n was to use and
  your find out more about your opinions.
  We use the questionnaires and your interview feedback to see what impact Settlel'n has
  on residents and staff.

### **BENEFITS:**

free training high street vouchers certificates for your professional development experience being involved in research and working with University College London.

#### Slide 5

## SettleIN Programme Structure and How to do it

- Modules (a series of activities)
- 4 week programme of activities
- do each activity (combine SettleIN activities with usual care as well as separately)
- record progress and resident's response
- Future Planning Conversation
- review of progress on module activities after four weeks
- Think about how activities can be continued.

## Slide 6

## **SettleIN Modules**

- Orientation getting to know their way around and feel safe
- Lifestyle routines and stimulation Family and Friends – staying connected and keeping family informed
- Identity being known, respected and understood

#### Optional module:

Struggling to Engage- Supporting residents who seem disengaged or isolated

For each activity write down the information gathered on the forms provided

Work through workbook modules, amiliarise, ask questions, practice explaining module to staff colleague hink about times in usual care in which SettleIn activities could also be completed

#### Slide 7

## Module and Activities Monitoring & Recording

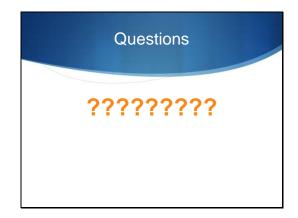
#### When delivering the modules:

- Each time an activity is done:
  - Each time an activity is done:

    Use SetIteIN Recording Progress Sheets to record brief notes about what was done, by whom and how the resident responded. Also note how you felt.

    These should be brief and similar to recording care plan progress notes/end of shift notes
- Tick off when an activity has been done on the SettleIN Module Tracker. Use the SettleIN Module Tracker to assess how much of a module has been completed and how much is yet to be done.

#### Slide 8



## **SettleIN training handouts**

## **SettleIN Training: Factsheet**

#### What is SettleIN?

- A programme for care home staff to help new residents with dementia quickly and successfully adjust to their new home
- Manualised programme
- Aims to promote healthy, positive adjustment

#### How the research works:

- Residents will be randomly allocated to the SettleIN group (involves care staff and new residents with dementia testing the SettleIN programme) or the care as usual group (new residents receive standard care from care staff in their new care home)
- Before starting the programme we complete questionnaires with the resident, you, and if possible the resident's family
- ♦ You run SettleIN
- We repeat the questionnaires at the end of four weeks once SettleIN is finished
- We repeat the questionnaires again four weeks later (follow-up)
- We interview you (a 30 minute chat) about how easy (or not!) SettleIN was to use and find out more about your opinions
- We use the questionnaires and your interview feedback to see what impact SettleIN has on residents and staff

#### The benefits of taking part:

- Free training
- High street vouchers
- Certificates for your professional development
- Experience being involved in research and working with University College London (UCL).
- You will have made a major contribution to a programme to improve the lives of care home staff and new care home residents with dementia.

#### What do we mean by healthy adjustment?

- Adjustment is the process of adapting or becoming used to a new situation (Oxford Dictionaries Online, 2010).
- ♦ Healthy adjustment is the process of adapting or becoming used to a new situation in a positive way without negative side effects such as depression or rapid cognitive and physical decline

#### What does research says about adjustment?

- There are positive factors that can help adjustment: new residents being in a home-like environment, having a buddy system, working with families where possible, doing activities that are meaningful to the resident.
- There are also negative factors which are detrimental to adjustment: loss of familiar surroundings, lifestyle and people, feeling abandoned by family.

• SettleIN aims to incorporate the positive factors into resident's experience of moving in as well as protecting against the negative factors that may occur.

## Support

- ♦ Contact Judy Murrill or Caroline Saint:
- •
- •

## Appendix G

## **Quantitative Measures and Checklists**

Demographics recording sheet and measures checklist

Usual adjustment support checklist

## **Demographics Recording Sheet and Measures Checklist**

## **Baseline Measures**

ITEM	DATA NEEDED	DATA
1	Resident Name / Admission Date	
2	Resident Participant Code	
3	Age	
4	Dementia Diagnosis	Vascular Alzheimers Other:
5	First Language	
6	Ethnicity	
7	Religion	
8	Past Occupation	
9	Nationality	
10	Family	Involved Not known/not involved Other:
11	Physical Health	
12	Medication	
13	Marital Status	
14	GP details	
15	QoL-AD collected	
16	IRA collected	
17	CSDD collected	

## Staff/Key workers likely to lead/be involved in SettleIN for this person

1	Staff Name	
2	FAST	
3	Demographics Collected	
4	CSDD Collected	
5	QoL-AD Collected	
6	SCIDS Collected	
7	ADQ Collected	

## Care home

1	Care home name	
2	Usual care home adjustment support checklist	

## Usual adjustment support checklist

Adjustment support	YES/ NO	Further information
Buddy system		
Orientation Programme		
Preferences asked about		
Background information asked about		
Life books created with resident		
Procedures to keep family members informed about residents wellbeing		
Anything else		

## Appendix H

## Qualitative analysis

Staff interview schedule

Interview coding exemplar

Sub-themes exemplar

Themes, sub themes and codes from interview data

### **Staff Interview Schedule**

**Feasibility Questions** 

What has your experience been of delivering the programme?

What worked? What didn't work?

What challenges have you experienced?

How easy or difficult has the programme been to do alongside your day to day work?

How easy or difficult has it been to finish the programme in the 4-6 weeks?

What do you think other care home staff would think of this programme?

Would you suggest any particular changes to the programme?

Adjustment Questions (analysed by Murrill)

What is your understanding of adjustment?

Has completing SettleIN changed your understanding of the adjustment process? If so, in what ways?

Has your knowledge of how to support somebody to adjust changed?

What do you think needs to happen for a new resident to adjust well?

What can you as care home staff do to support adjustment? What needs to happen within the care home to support adjustment?

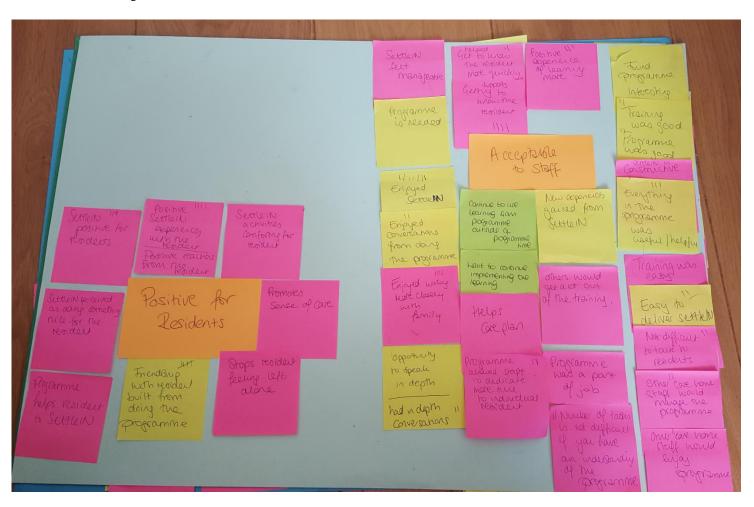
Before doing this programme what were your expectations of how well a new resident would adjust? Have these expectations changed since completing the programme?

Was any part of this process helpful for your professional development?

## Interview coding exemplar

193	Ok. What do you think other care home staff would think of the programme?	
194	ok. What do you think other eare nome stajj would think of the programme:	
195	think, they'll benefit too, they will benefit from all of this, because it helps you to	Commented [CS1]: Other staff would
196	write down the care plan and thinking of putting all of this in mind, so, umm, that is	Commented [CS2]: Helps with care plan
197	a lot of involvement, umm, that is somebody is feeling, valued, somebody is feeling	Commented [CS2]. Helps with care plan
198	valued, and they don't look at themselves like, they are just there, they are just there,	
199	they are actually individuals, they have lives, they still have their lives to lead, it is not	Commented [CS3]: Helps to think of residents
200	like you have just abandoned them, so I think other people, other homes are going	as individuals  Commented [CS4]: Preventing resident feelings
201	to enjoy this, and no knowledge is wasted, so in writing our care plans you can fit all	of abandonment
202	of this together, and you will write a better care plan.	Commented [CS5]: Other homes will enjoy the programme
203		Commented [CS6]: Care plan will be better as a result of this programme
204	So it sounds like it is useful for writing the care plan	a result of this programme
205		
206	Yeah. It is useful for creating the care plan, and it is useful too for the individual	
207 208	settling in, you know that there are people that actually do care, and you are not left alone.	Commented [CS7]: Useful for resident- promotes sense of care
209	iert alone.	Commented [CS8]: Programme stops residents
210	Something about that relationship between the staff member and the resident	being left alone
211		
212	Yes, definitely, between staff members.	
213		
214	Would you suggest any changes to the programme, in light of any difficulties you've	
215	had with it with your job role and the timing, and wanting more support, would you	
216	suggest anything we could do umm to make it easier for you?	
217		
218	I don't know whether, umm, it would be nice for one person to work with us, I think	Commented [CS9]: Programme would be
219	it'll be a good thing for one of you to work with us, because we lean on each other	improved with more external support
220	and, I can see what you do and try to fit it to, we work together and make life different	Commented [CS10]: Work more closely
221	for the resident and actually try to enable to settle.	with researchers
222		
223	So more support from researchers	
224		
225	Yeah	
	1	

## **Sub-themes exemplar**



## Themes, sub-themes and codes from interview data

Thomas	Cub thomas	Codos		
Themes	Sub themes	Codes		
Organisational	Existing heavy workload	Job is tiring		
barriers		Heavy workload		
		Job is stressful		
		Doing the programme got in the way of day to day job		
		Working long hours is difficult		
	Existing task focused approach	Can't sit in one place and focus on one thing		
		Non care tasks need doing		
		Difficult to leave other residents to do the programme		
		Unable to focus attention on one resident		
		Care tasks need to be logged and recorded		
		Already have a lot of training as part of job role		
		Multiple care tasks need to be done		
		Can't do programme in the mornings		
	Difficult to find the time	Had to work on programme outside of work hours		
		Don't have time to sit and talk		
		No free time		
		No time for staff to have a break		
		Job is too busy		

Had to make time to do the

programme

Absence of managerial facilitation

Short staffed

Don't see resident if shift is

based in another unit

Change of shift pattern delayed the programme

Not assisting resident

everyday

Programme factors acting as barriers

Documentation was challenging

Documentation was time

consuming

Too many pages of documentation

Had to document outside

of work hours

Have to go back and document at a later time

Documentation was

confusing

Difficulty documenting

**Documentation** was

stressful

Finding time to write was

challenging

Concern about resident's perception of using the

paper

Multiple other writing tasks

to do

Remove detailed SettleIN

documentation

All documents should be

on one page

Prefer programme documentation to be

electronic

Inflexibility of programme structure affect programme completion

Took longer than scheduled to complete weeks

Annual leave makes it difficult to complete programme in 4-6 weeks

Delays in programme due to outside factors

Delays due to resident's physical health problems

Didn't finish the programme

Programme should be more flexible

Time off sick days delays the programme

Individual resident factors

Dementia severity affected implementation

Level of communication affects the programme

Resident factors meant resident didn't understand the programme

Challenge of working with severe dementia

More suited to earlier stages of dementia

Abilities of resident were

changeable

Resident difficult remembering answers

Resident preference affected engagement Delays the programme when a resident doesn't

engage

Resident wants to be left

alone

Individual resident factors meant that the client

engaged

Resident didn't want to do SettleIN activities

Resident's mood impacted on resident engagement

Resident's health impacted on resident engagement

Residents personal life experience affected engagement in some tasks

## Acceptability of SettleIN

SettleIN is difficult for staff

Some conversations emotive

Experienced programme as stressful

Programme is extra to job role

Lots of tasks to complete

Programme was daunting at first

National and the same of the s

Other care home staff would find it difficult

Feeling uncomfortable

Less chatty staff may find it more difficult

SettleIN content is acceptable to staff

New experiences gained from SettleIN

Others would get a lot out of the training

SettleIN is enjoyable

SettleIN is needed

Love the programme

Felt manageable

Programme is enlightening

Want to continue implementing the programme

Opportunity to speak in depth

Positive experience of learning more

Found programme interesting

Training was good

SettleIN is constructive

SettleIN is helpful

Training was easy

Easy to deliver SettleIN

Programme was seen as part of job role

SettleIN is positive for residents

Doing something nice for the resident

Positive reactions from the resident

SettleIN activities comforting for residents

Promotes sense of care

Helpful for staff and resident

Noticed a big difference in resident

Resident is more independent

Programme stops residents being left alone

Friendship built with resident from doing the programme

Supports getting to know the resident

Got to know the resident more quickly

# Overcoming challenges

External support is needed

Helpful to do programme alongside other staff

Importance of colleague support

Need for colleagues to pick up care tasks when doing SettleIN

More extensive training is wanted

Thought there would be more external support with the programme

Adopting problem solving

Using other means to document programme

Using family members for information

Flexibility in time taken to do activities

Rely on workbook

Try and fit the programme into day to day practice

Persevering with programme despite difficulties

Work out the best time of day to do the programme

Planning was important to implementation