Healthy adjustment for new residents with dementia using SettleIN: a feasibility study with staff in UK care homes.

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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.

Signature:

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Overview

Volume one of the thesis is presented in three sections. Part one presents a mixed studies literature review exploring family involvement with care homes following placement of a person with dementia. The 26 included papers are presented according to methodology and research question which encompassed types of family involvement, influences on involvement, family involvement interventions and their outcomes for residents. This is followed by a discussion comparing the last decade of developments to an earlier seminal review on family involvement with care homes.

Part two is an empirical paper reporting a study that investigated the feasibility of SettleIN, a staff led healthy adjustment intervention for new care home residents with dementia. The process of intervention development and mixed method results of stakeholder consultation are reported. This is followed by a description of the intervention trial and outcomes for feasibility and resident quality of life and mood.

Part three provides a critical appraisal of the literature search and major research project. Methodological challenges encountered and decisions made in the process of undertaking both parts of the work are discussed. Key learning points are highlighted throughout and proposals are made for future research.

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Part I: Literature Review

Family involvement with care homes following placement of a relative with dementia: A mixed studies review of the literature

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Abstract

Aims: This review aimed to understand the last decade of development in family involvement with care homes following placement of a relative with dementia. Types of involvement, factors influencing involvement, how family involvement is promoted within care homes and, involvement impact on resident quality of life and behavioural and psychological symptoms of dementia (BPSD) were considered.

Method: The PsycINFO, MEDLINE and CINAHL Plus databases were searched for papers published between January 2005 and December 2015. Twenty-six papers representing 25 studies were included in the review and appraised using a quality rating tool designed for use with mixed study designs.

Results: The studies were found to be of a reasonable quality though some weaknesses were apparent. Sixteen papers highlighted types of involvement. Fourteen papers pertained to factors influencing involvement. Six studies of interventions designed to enhance at least one type of family involvement found positive changes in communication and family-staff relationships. Improvement in resident BPSD was reported in one randomised controlled trial promoting partnership. Visit frequency was associated with BPSD reduction for residents with moderate dementia. Family involvement was also related to positive quality of life benefits for residents. Contrasting results across the studies made definitive conclusions difficult.

Conclusion: The evidence suggests that involving families can be beneficial for families, staff and residents. Nevertheless, there may be some conditions in which involvement has no effect or a negative effect for residents. Overall, many families desire partnership, to be an active advocate and to focus on care monitoring and evaluation. However, there is inter-family variation in the level and nature of their preferred involvement. Many early proposals for further research have yet to be extensively adopted. Further evidence refinement is recommended.

Introduction

Family involvement (FI) with care homes following placement of a relative with dementia is vital in our current care climate. FI forms part of the recommended person-centred care approach (van der Steen et al., 2014) and has been linked with positive outcomes for residents, families and staff (Castro-Monteiro et al., 2016; Maas et al., 2004). In the UK and following the Winterbourne View (Department of Health (DOH), 2012) and Francis (The Mid-Staffordshire NHS Foundation Trust, 2013) reports, FI is central to ensuring increased transparency and partnership between care provider and client (Care Quality Commission (CQC), 2015; DOH, 2013; van der Steen et al., 2014) alongside national care quality assessment.

Approximately one-third to one-half of people with dementia in high income countries, and approximately six percent of those in low and middle income countries are cared for in long-term care facilities (Prince et al., 2013). With 46.8 million people worldwide living with dementia in 2015 and this number predicted to double every 20 years for the foreseeable future, it is probable that residents with dementia will remain the majority service user group in care homes (Alzheimer's Disease International, 2015). Care providers may increasingly turn to and benefit from families' assistance with facilitation of high quality of care for residents (Port et al., 2003). While not every care home resident with dementia has family or has family available and willing to engage, understanding the nature and impact of FI with care homes may provide insights into improved care processes that benefit all residents.

Definition

FI has been described as a multidimensional construct that entails visiting, socio-emotional care, advocacy and the provision of personal care (Gaugler, 2005; Reid, Chappell, & Gish, 2007). In a healthcare context, family refers to non-professional carers or caregivers including parents, partners, siblings, children, friends or other people who provide substantial support to a person receiving healthcare services (Eassom, Giacco, Dirik, & Priebe, 2014).

Prevalence

The prevalence of FI with care homes following the placement of a relative with dementia is a small, growing field of research. A study of 276 caregivers of people with Alzheimer's who had been residing in care (from one month to 21 years) found that 76% visited those they care for once a week or more (Tornatore & Grant, 2002). Another study involving caregivers of 353 residents with dementia randomly selected from 44 care facilities, reported spending an average of 4 hours a week interacting with their relative (Port et al., 2005). This trend was echoed in later research where 70% of caregivers for 323 people with dementia drawn from over twenty care homes reported visiting between one and seven hours each week (Grabowski & Mitchell, 2009).

Theory

Theoretical frameworks for FI have predominantly focussed on; person-environment fit and interaction (Kahana, 2003; Powell Lawton, 1975), role theory (Biddle, 1986), family systems theory (Minuchin, 1974) and stress theory (Pearlin, Mullan, Semple, & Skaff, 1990). In essence, the theories posit that person-environment fit and interaction alters over time for residents with dementia, family and staff. Environmental interventions are tried in the pursuit of stress reduction and to meet the evolving needs of the resident as dementia progresses. Families are challenged to adapt their inter-generationally established and stable patterns for communication and interrelation to cope with a relative's long term care placement. Levels of stress and burden change as social positions and caregiver roles and role nature (the number of roles, intensity, ambiguity, expectations, skill demand, conflict, norms and behaviours) change.

Existing literature reviews

In 2005, a major review of approximately 100 studies pertaining to FI in residential long-term care was published (Gaugler, 2005). The review focussed primarily on USA based research. Specific reference was made to eight studies involving residents with dementia. Findings highlighted that family members 1) continued to participate in their relatives' lives though the frequency and duration of visits fluctuated, 2) continued to remain socially involved with residents and 3) proposed other types of involvement beyond activities of daily living including supervision and monitoring of quality of care. More frequent family visits tended to occur when stronger family-resident relationships and social resources were in place. Education level, at-home care periods, length of stay in care home and frequency of behavioural difficulties before placement were also identified as influencing factors.

The review supports the link between family visits and benefits for residents such as reduced infections and hospitalisations. It also highlights a lack of studies exploring FI and resident psychosocial outcomes. Three FI intervention studies were reported in the review. One found improvements in family-staff communication, another established family-staff partnerships and the third intervention demonstrated a reduction in family-staff conflict. Findings from a paper related to one of the same interventions (though not reported in the Gaugler (2005) review) indicated that the Family Involvement in Care (FIC) intervention had beneficial effects for family and staff though no significant benefit for residents (Maas et al., 2004). While all of these studies appear to demonstrate a positive impact for families from their involvement with care homes, it remains uncertain whether overall, FI interventions have a positive influence on resident outcomes such as quality of life. With the synthesis being over ten years old it is not apparent if there have been any changes in this arena.

Petriwskyj et al. (2014) conducted a review of 26 studies published between

1990 and 2013, primarily looking at FI in decision making for people with dementia in residential aged care. Results indicated FI is complex and varied; family roles and role acquisition, perceptions and preferences all vary. While advocacy was highlighted as an important role, family caregivers are not always involved in, or consulted in decisions, and do not always know their relatives' preferences, or give great weight to these preferences in decisions. Even when positive outcomes are not evident for the person with dementia, the decision maker may still report satisfaction with the decision. This review offers an insight into the advocacy role of family members and factors influencing participation such as good family-staff communication and trust. However, it was limited to decision making aspects of FI and primarily focussed on choices relating to medical issues.

A recent meta-ethnographic review by Graneheim et al. (2014) involving 10 studies and 180 family caregivers from six countries, published between 1992 and 2012, found family caregivers described their experiences of relinquishing the care of a person with dementia as a process. A process that went from family caregivers being responsible for the decision, through living with the decision, adjusting to a new caring role (becoming a spokesperson) and having changed relationships (maintaining the relationship with the person with dementia and creating new relationships with professional caregivers). While role change and adjustment were highlighted in this review, interventions for FI and promotion of FI following placement of a resident with dementia were not considered.

Measurement

To date, a single, comprehensive and robust measure that addresses the multifaceted domains of FI does not appear to have been developed. The Murphy et al. (2000) Involvement scale measures participation in a range of care activities, such as contact through telephone calls and letters, laundry, helping the resident walk, engagement in games and monitoring finances. Despite the variety of activities included, the scale has been frequently modified by other researchers to ensure it is fit for purpose. For an example of this see Zimmerman et al. (2013). The family perceptions of caregiving role (FPCR) is a measure that includes elements related to FI such as role deprivation though its main focus is family member wellbeing (Maas & Buckwalter, 1990).

Reid, Chappell, and Gish (2007) explored two measures; the family perceived involvement (F-INVOLVE) comprised of 20 items and the importance of involvement (F-IMPORTANT) comprised of 18 items. These measured the extent to which families perceive they are involved in the care of their relative and the importance they attach to being involved in the care of their relative. The study (N=68) highlighted evidence of validity and reliability for the scales. In a recent study with a larger sample (N=150) further evidence for measure reliability was accrued (Irving, 2015).

In another study (N=116) the Family Visit Scale for Dementia (FAVS-D) was developed to measure the quality of visits between family caregivers and residents with dementia (Volicer & DeRuvo, 2008). This also demonstrated acceptable reliability and validity. To date, with the one exception already mentioned above, there do not appear to have been any additional papers published regarding the psychometric properties of these instruments.

Current literature review

The current literature review aimed to build on Gaugler’s (2005) synthesis of FI with care homes by providing an update on global developments over the last ten years with specific reference to families of residents with dementia. Understanding if there has been any expansion in the types of FI and influences on FI over the last decade will contribute to determining if family-care provider partnerships have evolved and increased in transparency. Furthermore, Gaugler (2005) recommended that future research be longitudinal in design, demonstrate links between FI and resident outcomes and interventions be evaluated in order to refine the literature. To address whether this proposal has been adopted by researchers in the dementia field, the current review will include time series and intervention studies aimed at promoting FI. Change in family-care home involvement and outcomes for residents with dementia will be considered.

Shedding light on progress made and narrowing the focus to dementia is important to develop consistent, tailored and evidence-based best practice guidelines. Literature has already established the importance of caregiver burden (Adelman, Lyubov, Delgado, Dion, & Lachs, 2014; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014; Wolfs et al., 2012) and its contribution to transitions and post-placement involvement (Garity, 2006; Gaugler, Pot, & Zarit, 2007) so it will not be a primary focus in this review.

Literature review questions

The review addressed the following research questions:

1. What types of involvement do families have with care homes following placement of people with dementia?
2. Which factors influence family involvement with care homes?
3. How have care homes promoted family involvement and which interventions have been trialled?
4. Does family involvement with care homes have a positive effect on residents' behavioural and psychological symptoms of dementia (BPSD) and quality of life?

Method

This literature review is based on the York Centre for Reviews and Dissemination (University of York, 2009) guidelines on conducting systematic literature reviews in health care. To build on Gaugler (2005) and explore the increasing emphasis on transparency and partnership between care homes and families, the current review focuses on studies published since 2005. The full inclusion and exclusion criteria are:

Inclusion criteria

- Randomised controlled trial (RCT) designs, quasi-experimental designs, interrupted time-series designs with the family member or family member and their relative as own comparison and qualitative studies.
- Families with a relative with dementia residing in a residential care home or nursing home.
- Studies where N ≥ 10.
- Published in English in peer-reviewed journals between 2005 and 2015.
- Training or interventions for families (or families and residents) that pertained to family involvement or partnership with long-term care providers and related resident psychosocial outcomes.

Exclusion criteria

- Studies, training or interventions solely set in home care, assisted community living or inpatient settings.
- Training or interventions for staff and/or residents that do not involve families.
- Family interventions focused solely on physical, medical or non-psychological outcomes e.g. decisions about psychotropic medication.
- Studies focused exclusively on caregiver burden, stress or wellbeing.
- End-of-life or advanced care planning studies where family involvement was not of primary interest.

Search strategy

The databases PsycINFO, MEDLINE and CINAHL Plus were searched in January 2016. Key terms were entered into Keyword and Subject heading searches in order to find studies pertaining to family involvement (‘family’, ‘families’, ‘informal caregiver’, ‘involvement’, ‘engagement’, ‘participation’, ‘role/roles’, ‘interaction’, ‘visit/visiting’) within a care home setting (‘care home’, ‘residential care’, ‘residential aged care’, ‘nursing home’, ‘skilled nursing facility/facilities’, ‘institutionalisation’, ‘long-term care’) for relatives with a diagnosis of dementia (‘dementia’, ‘Alzheimer’s’, ‘Alzheimer’s disease’). Key phrases were also used to ensure a broad search (‘working with families’ and ‘family-staff relationships’).

The papers ensuing from the search criteria were reviewed by title, abstract and full paper according to the inclusion and exclusion criteria. A snowball sampling strategy was used as reference lists from systematic reviews and each selected paper were examined to identify additional studies.

Quality rating

The Mixed Methods Appraisal Tool (MMAT) – Version 2011 developed by Pluye et al. (2011) was chosen to assess the quality of studies selected for review as it enables the rating of the methodology of qualitative, quantitative and mixed methods studies. Permission to use the MMAT was obtained from the authors.

Ratings of quality were based on a 21 criteria checklist involving two screening questions for all studies and five sections; qualitative (four criteria), quantitative (randomised, non randomised and descriptive, all with four criteria each) and mixed methods (three criteria). The sections and subsets of criteria were applied according to the type of study being reviewed. Responses to rating questions included ‘Yes’, ‘No’ and ‘Can’t tell’.

Papers received a score denoted by descriptors *, **, ***, and ****. For qualitative and quantitative studies, this score is the number of criteria met divided by four with scores varying from 25% (*) with one criterion met to 100% (****) with all criteria met. For mixed methods studies, overall quality is the lowest score of the study components. Criteria included quality of data sources, consideration of researcher influence and sample recruitment bias, as well as data outcome completion and drop out rates (see Appendix A).

Classification of studies

In order that the current literature review may be used to answer the questions posed, the selected studies were classified according to the aspect of FI explored. Studies were divided into two tables by methodology and then into three categories (see Table 1 and 2). The categories were 1) types of FI and/or influences on FI, 2) interventions and/or resident outcomes and 3) both.

Analysis and synthesis design

A convergent approach (Creswell, Klassen, Plano-Clark, & Smith, 2011) was predominantly employed for reporting the review findings in relation to each research question.

Results

Included studies

A total of 218 papers were identified from the database searches, 154 of which were excluded based on the above exclusion criteria and a review of titles, as they were deemed unrelated to the review topic. Following an abstract review, a further 44 papers were excluded; two were deemed unrelated to the review topic, ten were not specific to family involvement, six related to non care home settings, three related to measure development, six focussed on caregiver grief or burden, four pertained to biomedical, end of life and advanced care planning without emphasis on family involvement, eight were reviews, editorial or protocols only and five involved samples of less than ten. The paper identification and eligibility process is depicted in Figure 1 and shows that following a full text paper review (n=21) a further eight papers were excluded. Two-thirds of the thirty-five additional papers identified through hand and reference list searches were excluded (n=22). Therefore, 26 papers (classified in Table 1 and 2) remained for inclusion. They reported studies with quantitative or mixed methods (n=14) and qualitative designs (n=12). Research was primarily conducted in USA (n=11), Canada (n=6) and Australia (n=4). A paper from each of Japan, Taiwan, Norway, Sweden and the UK was found.

Two papers reported results from the same study (Bramble, Moyle, & McAllister, 2009; Bramble, Moyle & Shum., 2011). Data from a study was investigated in three different ways and reported separately (Dobbs et al., 2005; Port et al., 2005; Zimmerman et al., 2005). In another instance, two papers used data from one study (Reinhardt, Boerner, & Downes, 2015; Reinhardt, Chichin, Posner, & Kassabian, 2014). Finally, an additional two papers used data from a further study (Chappell, Kadlec, & Reid, 2014; Reid & Chappell, 2015). Therefore, 26 papers representing 25 studies drawn from 21 unique data sets were included in this review.

Study design and quality

Quality ratings ranged from * to **** (see Table 3) indicating a wide variation in study quality. Despite this, the majority of the studies scored *** or above and showed methodological strengths in setting out study objectives, including multiple sites in their samples and applying site randomisation, describing analyses, use of verification procedures and drawing conclusions in line with results. The remaining studies rated in the review were of low to medium quality, receiving ratings between * and **. Generally, studies had appropriate study designs for the questions posed

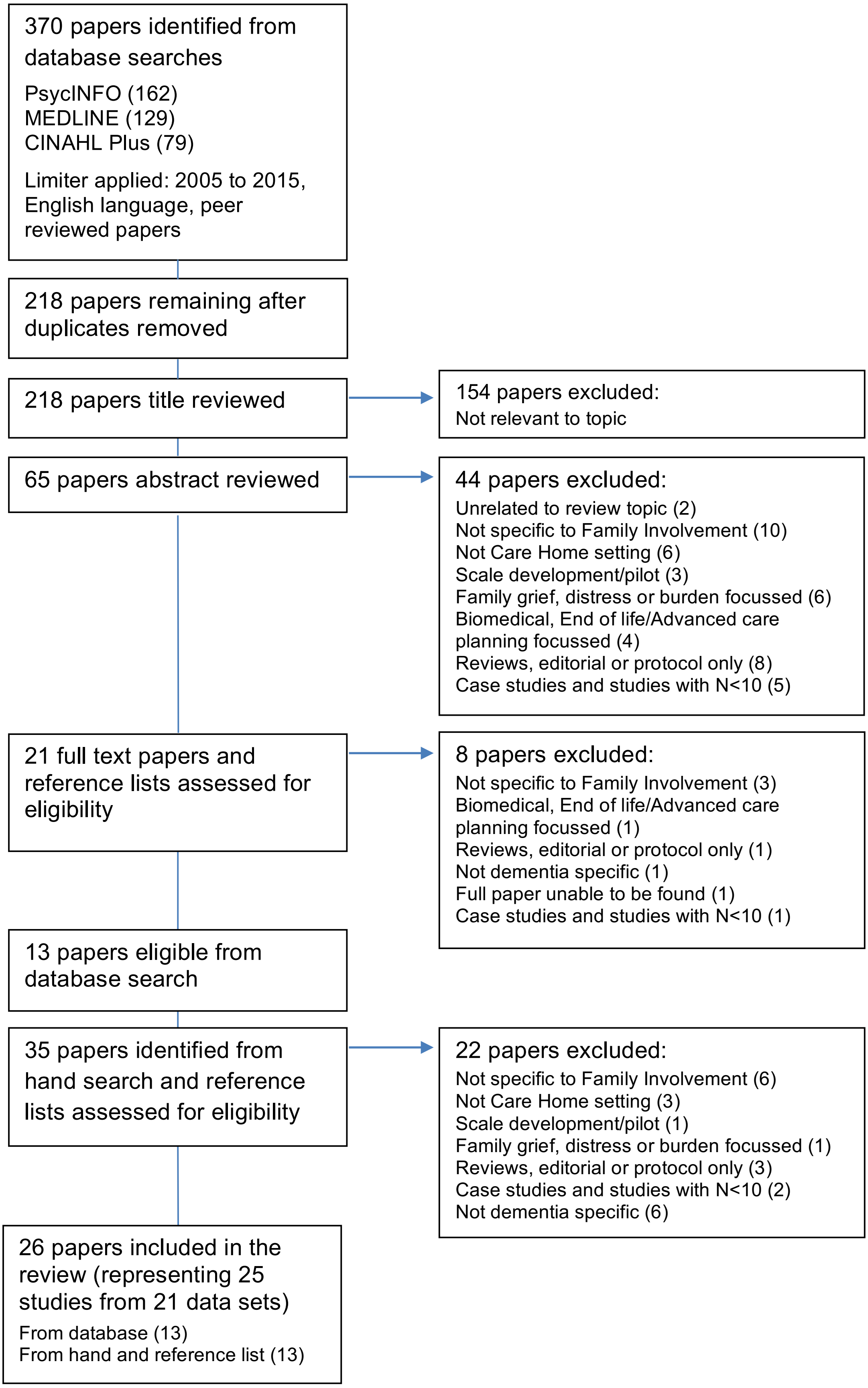

Figure 1. Flowchart of literature identification and eligibility.

and conclusions that were supported by their results. However, some studies did not appear to consider power, their sample size was too small for analyses conducted and they had high attrition rates, while the quality of other studies were reduced by incomplete data collection or result reporting.

Research questions

1. *What type of involvement do families have with care homes following placement of people with dementia?*

FI is complex, multidimensional and potentially unique for each family. 16 out of the 26 papers included in this review informed the varied and related types of FI shown in Table 4. Of the three cross-sectional analyses, five correlational longitudinal analyses, a descriptive analysis and five qualitative studies, two achieved MMAT scores of ** or below. Findings remain included as other studies identified similar types of FI.

Reid and Chappell (2015) found that families perceived there to be fewer opportunities for participation in the very types of involvement they deemed to be most important; ensuring a well cared for relative, active development of trust in staff, inclusion in decision making and being informed about care plan changes. Five studies considered types of involvement alongside satisfaction and confidence in care and found contrasting results (Gladstone, Dupuis, & Wexler, 2006; Grabowski & Mitchell, 2009; Helgesen, Larsson, & Athlin, 2012; Levy-Storms & Miller-Martinez, 2005; Reinhardt et al., 2015). While satisfaction with care was highest where families had minimal or no involvement with care homes (Grabowski & Mitchell, 2009), for other families, the more they were involved in discussions with staff the greater their satisfaction with care (Reinhardt, et al., 2015).

Furthermore, FI in the provision of personal and instrumental care prior to placement was related to lower levels of satisfaction with care, provided by the care

Table 1

Papers reporting studies with a quantitative or mixed method design classified by research question

Authors	Method, approach and setting	N	Key FI domain, measures and time points	Key results	Quality rating and Comments
Included types and/or influences of family involvement					
Cohen et al., 2014 (USA)	Correlational (cross-sectional) Investigated caregiver involvement for residents with dementia 24 Long-term care facilities 1 USA state	*Family* 467 *Residents* 467 *Staff* 381	*Family* FI visits (Involvement) *Resident* Cognition (MDS-COGS); Function (MDS-ADL); Function (IADL) *Staff* FI visits (Involvement) Baseline	Families reported sig greater visits than staff, no sig difference in visit frequency by dementia severity, Families of residents with dementia spent sig more time on activities of daily living (ADL) and staff discussion than families of residents without dementia	*MMAT*: **** Pos: Large sample, power, measures, adjustment for clustering effects Neg: Visit exclusions Inconsistent variance reporting
Levy-Storms & Miller-Martinez 2005 (USA)	Correlational (longitudinal) Investigated relationship between involvement and satisfaction with care > 70% Care homes	*Family* 145 *Residents* 145	*Family* Satisfaction with care (11 areas); Involvement (type of assistance, frequency of visits) *Resident* Behavioural problems (Caregiver perception of resident's behavioural problems questionnaire) Baseline (admission) and 12 months	Family involvement in I/ADL was associated to level of care satisfaction, frequency of visiting was not. The more that families provided I/ADL assistance at admission, the lower their level of satisfaction 1 year later	*MMAT*: **** Pos: Analysis description, controls, reported variance Neg: Non-standardised measures, no power analysis, self-selected sample, attrition rate
Port et al., 2005 (USA)	Correlational (MM) (cross-sectional) Compared dementia care in residential care (RC)/assisted living (AL) to care homes 35 RC/AL, 10 Care homes 4 USA states	*Family* 353 *Residents* 353	*Family* Involvement (expenses, time visiting/talking, involvement, involvement preference, burden, and across 8 activities) *Resident* Independence (MDS-ADL); Cognition (MMSE; MDS-COGS) Baseline	No sig difference in visit/talking time or family preference for higher involvement, families desire more involvement and assistance in being involved	*MMAT*: *** Pos: Large sample, description of quantitative analysis, confound control, randomisation within site Neg: Site type recruitment, self-report reliance, power unclear, qualitative analysis description
Reid & Chappell 2015 (Canada)	Descriptive Investigated involvement opportunities and importance 18 Care homes 3 communities	*Family* 135 *Residents* 149	*Family* Involvement importance (FICS-FII) and Perceived opportunities for involvement (POI) and involvement congruence (FICS-T) Baseline	Incongruence of opportunities over importance for seven types of involvement. A lack of opportunity for important types of involvement.	*MMAT*: **** Pos: Sample, power, description of sample selection, measure refinement, response rate Neg: Single informant

Table 1 *(Continued)*

Authors	Method, approach and setting	N	Key FI domain, measures and time points	Key results	Quality rating and Comments
Reinhardt, Boerner & Downes 2015 (USA)	Correlational (longitudinal) Investigated involvement and frequency of conversations about palliative care 1 Care home Northeast	*Family* 90 *Residents* 90	*Family* Frequency of discussion with staff across seven end-of-life (EOL) domains; *Resident* Cognition (CPS) Baseline, 3, 6 months	Just under half the families visited at least once per week, higher frequency of discussion was associated with higher care satisfaction	*MMAT*: *** Pos: Confound control, effect size, variance reporting *Neg*: Single site, small sample, sample selection bias not accounted for
Included involvement interventions and/or resident outcomes					
Bramble, Moyle & Shum 2011 (Australia)	CRCT (MM) Family Involvement in Care (FIC) intervention 2 Long-term care facilities	*Family* 57 *Staff* 59	*Family* Knowledge (FKOD); Stress (FPCR); Satisfaction (FPCT) *Staff* Knowledge (SKOD); Stress (SPCR; CSI); Attitudes towards family (AFC) Baseline, 1, 5 and 9 months	Sig increase in both family and staff knowledge of dementia, sig decrease in family satisfaction regarding staff consideration and management effectiveness.	*MMAT*: **** Pos: Randomised sites, blinding, power and attrition aims *Neg*: Small sample, follow up attrition, no variance reported
Chappell, Kadlec & Reid 2014 (Canada)	Correlational (longitudinal) Examined predictors of change in social skills among residents with dementia 18 Care homes 3 communities	*Family* 135 *Residents* 149	*Family* Involvement (F-INVOLVE); Involvement importance (F-IMPORT) *Resident* Social skills (MAS-R) Baseline (admission), 6, 12 months	FI was not a sig predictor of changes in resident social skills over time, larger decreases in social skills associated with smaller social networks and sig fewer total visits	*MMAT*: **** Pos: Power, analysis reporting, longitudinal (12m), CI reporting, measures, response rate *Neg*: Type I error risk
Jablonski, Reed & Maas 2005 (USA)	CRCT Family Involvement in Care (FIC) Intervention 14 Care home special care units Midwest	*Family* 164 *Residents* 164	*Resident* Cognition (GDS); Function (FAC) Baseline, 3, 5, 7, 9 months	Resident deterioration reversed initially though not sig different by 9 months, no sig effect on resident self care ability, inappropriate behaviour or agitation.	*MMAT*: ** Pos: Attrition adjustment, site randomisation, cluster effects considered *Neg*: blinding, no family description, power calculation or effect size, attrition

Table 1 *(Continued)*

Authors	Method, approach and setting	N	Key FI domain, measures and time points	Key results	Quality rating and Comments
Reinhardt et al., 2014 (USA)	RCT Palliative care conversation with follow up calls intervention 1 Care home Northeast	*Family* 90	*Family* Satisfaction with care (SWC-EOLD) *Resident* Symptom control (SM-EOLD); single item rating across seven EOL domains Baseline, 3, 6 months	Families had sig increased care satisfaction and had documented sig more end-of-life care decisions in care records, no sig difference in symptom management	*MMAT*: *** *Pos*: Randomisation, blinding, control group *Neg*: Sample size, no power calculation, description of randomisation
Robison et al., 2007 (USA)	CRCT (MM) Partner in Caregiving intervention adapted for Special Care Units (PIC-SCU) 20 Care homes 1 USA state	*Family* 388 *Staff* 384	*Family* Conflict (ICS); Staff Provision (SPRS); Staff Behaviour (SBS); Staff Empathy (SES); Hassle (NHHS); Family Involvement (FIS) *Resident* Agitation (CMAI) *Staff:* Conflict (ICS); Family Behaviour (FBS); Family Empathy (FES) Baseline, 2 and 6 months	Improvements in ease of talking with staff, and resident behaviours. Spouse/same-generation visits increased, number of programs offered to families increased.	*MMAT*: *** *Pos*: Sample size, 6m follow-up, confounding accounted for, response rates *Neg*: No variance reported, measure reliability
Included both involvement types/influences and/or interventions/resident outcomes					
Dobbs et al., 2005 (USA)	Correlational (cross-sectional) Compared dementia care in residential care (RC)/assisted living (AL) to care homes 35 RC/AL, 10 Care homes 4 USA states	*Family* 400 *Residents* 400	*Family* Frequency of visits *Resident* Activity involvement (PAS-AD); Time points: Baseline	Families visited at least once in the last week, family assessing activities and social involvement was related to more resident activity involvement.	*MMAT*: *** *Pos*: Large sample, adjustments, variance reporting *Neg*: No description of family participants, non-standardised facility measures, missing data
Grabowski & Mitchell 2009 (USA)	Correlational (longitudinal) Examined caregiver visit duration and resident quality end-of-life care 22 Care homes 1 USA city	*Family* 323 *Residents* 323	*Family* Oversight (visit hours per week); Satisfaction with care (SWC-EOLD) *Resident* Health and dementia severity (BANS-S); Quality of life (QUALID); Quality of care (seven domains) Time points: Baseline, quarterly for 18 months/death.	Most families spent between one and seven hours visiting each week, family satisfaction with care highest in group that did not visit, quality of care sig worse for residents visited over 7 hours per week.	*MMAT*: *** *Pos*: Longitudinal, large sample, confound control, variance and limitation reporting *Neg*: One non-representative, geographical site

Table 1 *(Continued)*

Authors	Method, approach and setting	N	Key FI domain, measures and time points	Key results	Quality rating and Comments
Minematsu 2006 (Japan)	Correlational (longitudinal) Investigated family visits and behavioural and psychological symptoms of dementia (BPSD) 1 Care home	*Residents* 67	*Family* Hours per week visiting/talking *Resident* Cognition (HDS-R); BPSD suppression (DBD) Time points: Baseline, 12 months	Majority of residents visited between none and ten times per month on average, frequency of visits associated with positive change in HDS-R and DBD in residents with initial moderate HDS-R, change was lower where visit frequency was above average.	*MMAT*: * *Pos*: Longitudinal (12m), measures, description of analysis, multiple appraisers *Neg:* Small single site sample, minimal description of participants and data collection, missing measure reference and limitations
Zimmerman et al., 2005 (USA)	Correlational (longitudinal) Compared dementia care in residential care (RC)/assisted living (AL) to care homes 35 RC/AL, 10 Care homes 4 USA states	*Family* 170 *Residents* 170	*Family* Frequency of visits *Resident* Activity involvement (PAS-AD); Quality of life (QOL in AD-activity); Behaviour (DCM) Baseline, 6 months	Families spent almost seven hours per week on average visiting or talking with the resident, FI was associated to higher resident quality of life.	*MMAT*: **** *Pos*: Longitudinal, randomisation within site, confound adjustments, limitation reporting *Neg*: Missing data, no power analysis or effect size

Note. AFC=Attitudes towards family checklist; BANS-S=Bedford Alzheimer's Nursing Severity subscale; CMAI=Cohen-Mansfield Agitation Inventory; CPS=Cognitive Performance Scale; CSI=Caregiver stress inventory; DBD=Dementia behaviour disturbance scale; DCM=Dementia Care Mapping; FAC=Functional Abilities Checklist; FBS=Family Behaviors Scale; FES=Family Empathy Scale; FIF=Family Involvement Instrument; FIS= Family Involvement Scale; FKOD=Family Knowledge of dementia test; FPCR=Family perceptions of caregiving role; FPCT=Family perceptions of care tool; GDS=Global Deterioration Scale; HDS-R=Hasegawa Dementia Scale-Revised; I/ADL= Instrumental Activities of Daily Living scale; ICS=Interpersonal Conflict Scale; Involvement = Murphy et al., 2000 Involvement scale; MAS-R= Multi-Focus Assessment Scale Revised; MDS- ADL= Minimum Data Set – Activities of Daily Living Scale; MDS-COGS=Minimum Data Set Cognition Scale; MMSE=Mini-mental State exam; NHHS=Nursing Home Hassles Scale; PAS-AD= Patient Activity Scale–Alzheimer's Disease; QUALID=Quality of Life in Late-Stage Dementia; SBS=Staff Behaviors Scale; SES=Staff Empathy Scale; sig=significant; SKOD=Staff knowledge of dementia test; SM-EOLD=Symptom Management at the End-of-Life in Dementia Scale; SPCR=Staff perceptions of caregiving role; SPRS=Staff Provision to Residents Scale; SWC-EOLD= Satisfaction with Care at the End-of-Life in Dementia Scale.

Table 2

Papers reporting studies with a qualitative design classified by research question

Authors	Method, Approach and setting	N	Key domain and time points (single unless stated)	Key results	Quality rating and Comments
Includes types and/or influences of family involvement					
Bramble, Moyle & McAllister 2009 (Australia)	Semi-structured interviews from MM study Descriptive 2 Long-term care facilities	*Family* 10 *Residents* 10	Meaning of being family of a relative with dementia who is placed in long-term care	Family sought connection and meaning with staff, evaluation of care spanned general satisfaction with the environment, level of physical care, attitude of staff, their friendliness and obvious sense of care for the patients who are there	*MMAT*: **** *Pos*: Description of thematic sequential analysis and steps to ensure rigour *Neg*: Small sample, researcher philosophy unclear
Caron, Griffith & Arcand 2005 (Canada)	In-depth interviews Narrative 2 Long-term care facilities	*Family* 24 *Residents* 20	Context of interactions with care providers when making EOL decisions	Four domains identified; quality of the relationship, frequency of contact, values and beliefs, and level of trust. Families seek a personalised relationship with staff	*MMAT*: **** *Pos*: Description of data collection, bias prevention, limitations *Neg*: Sample site description
Edvardsson, Fetherstonhaugh & Nay 2010 (Australia)	Interviews, focus groups 3 Long-term care facilities	*Family* 12 *Staff* 37	Content of person centred care (PCC)	PCC promoted a continuation of resident self and normality across five content categories including welcoming family, families aimed to develop and maintain trust in the staff to facilitate active communication about the resident, families desired that staff actively encouraged them to maintain the relationship and life they had with the resident	*MMAT*: ** *Pos*: Analysis by multiple researchers, sample variation *Neg*: Reflexivity, credibility, convenience sample
Gladstone, Dupuis & Wexler 2006 (Canada)	In-depth interviews Interpretivist naturalistic with thematic analysis 2 Care homes	*Family* 35	Family roles, activities and change factors Baseline, 12 months	Family visits increased over time and change in contact was associated with 4 conditions: personal, social, institutional (reduction in visits), and health (increased contacts).	MMAT: **** *Pos*: Large and maximum variation sampling, longitudinal design, negative case analysis *Neg:* Small site sample, visit data collection unclear and reliant on self-report

Table 2 *(Continued)*

Authors	Method, Approach and setting	N	Key domain and time points (single unless stated)	Key results	Quality rating and Comments
Helgesen, Larsson & Athlin 2012 (Norway)	Interviews Grounded theory 3 Care home special care units	*Family* 12	Family role in patient participation process Participants interviewed twice over one year	Experienced as transitions between different roles to secure the resident's well-being; visitor (pre requisite for other roles), spokesperson, guardian and link to outside world. Different situations triggered different kinds of role and role depended on different conditions	*MMAT*: **** *Pos:* Reflexivity, description of theoretical framework and analysis, two interviews *Neg:* Small sample, NH context details
Johansson et al., 2014 (Sweden)	Narrative interviews Descriptive with content analysis 6 Care homes	*Family* 10	Aspects facilitating and hindering the care relinquishing process	Family wish to remain connected despite separation, negative expectations of care and lack of information hindered relinquishment while being recognised as partners in care after placement facilitated relinquishment	MMAT: **** *Pos*: Methodological reflection and assumptions, circular and consensus based analysis *Neg*: Small sample, sample site profile unclear
Lau et al., 2008 (Taiwan)	Interviews Grounded Theory 1 Care home	*Family* 11	Family-staff process used for collaborative relationship development	Families applied Institutional social penetration (ISP) (constant interaction between self-disclosure, evaluation of care and penetration strategies) to develop family-staff relationships	*MMAT*: **** *Pos*: Credibility strategies, description of data collection and analysis *Neg*: Small sample, site description, partial reflexivity described
Legault & Ducharme 2009 (Canada)	Semi-structured Interviews Grounded theory 3 Long-term care facilities	*Family* 14 daughters	Change in advocacy role	Advocacy role evolved over time based on three related processes; development of trust, integration into the setting and evaluation of care quality	*MMAT*: **** *Pos*: Reflexivity, bias prevention, reporting *Neg*: Missing sample group
Majerovitz, Mollett & Rudder 2009 (USA)	Interviews, focus groups, survey Grounded theory 32 Care homes	*Family* 103 *Staff* 446	Staff-family communication and cooperative partnership	Multiple hindrance factors including poor staff-family communication, inadequate information, supervisors being unwilling to hear negative feedback, understaffing or erratic staffing; family guilt, hypervigilance, dissatisfaction with care, and unrealistic expectations	*MMAT*: *** *Pos*: Description of research questions and included studies *Neg*: Method description, credibility, sample selection

Table 2 *(Continued)*

Authors	Method, Approach and setting	N	Key domain and time points (single unless stated)	Key results	Quality rating and Comments
Strang et al., 2006 (Canada)	Interviews Descriptive Facility type unknown	*Family* 15	FM experience after relative placement Final point ≤ 3months post placement	Family relationships with resident did not change after placement, families engaged in numerous care tasks to maintain continuity, retain control, demonstrate commitment to others, and assuage guilt and ambivalence	*MMAT*: *** *Pos*: Credibility process and analysis description *Neg*: Reflexivity, care facility reporting
Includes involvement interventions and/or resident outcomes					
Aveyard & Davies 2006 (UK)	Semi-structured interviews, focus group Action group intervention (Senses Framework) 1 Care home	*Family* 7 *Staff* 18	Collaborative working between residents, relatives, staff and researchers	Families and staff created a shared understanding, learned to value each other, became a powerful voice for change and moved forward.	*MMAT*: **** *Pos*: Longitudinal design, member checks, researcher influence, limitation reporting *Neg*: Small sample, atypical single site
Includes both involvement types/influences and/or interventions/resident outcomes					
Stirling et al., 2014 (Australia)	Interviews, focus and action groups Dementia and Dying: discussion tool 4 Care Homes	*Family* 11	Facilitation of staff-family communication about palliative care	Families and staff reported the tool promoted a different type of communication where families were engaged, confidence in talking about dementia trajectory and palliative care was improved and family-staff relationships were enhanced.	*MMAT*: *** *Pos*: Description of tool development, stakeholder review *Neg*: Small sample, no result verification, researcher influence unclear

Table 3

Mixed methods appraisal tool (MMAT) scores for included studies

Study	MMAT
Quantitative studies	
Minematsu (2006)	*
Jablonski , Reed & Maas (2005)	**
Dobbs et al. (2005) [a]	***
Grabowski & Mitchell (2009)	***
Reinhardt et al. (2014) [b]	***
Reinhardt, Boerner & Downes (2015) [b]	***
Cohen et al. (2014)	****
Chappell, Kadlec & Reid (2014) [c]	****
Levy-Storms & Miller-Martinez (2005)	****
Reid & Chappell (2015) [c]	****
Zimmerman et al. (2005) [a]	****
Qualitative studies	
Edvardsson, Fetherstonhaugh & Nay (2010)	**
Majerovitz, Mollett, & Rudder (2009)	***
Stirling et al. (2014)	***
Strang et al. (2006)	***
Aveyard & Davies (2006)	****
Caron, Griffith & Arcand (2005)	****
Gladstone, Dupuis & Wexler (2006)	****
Helgesen, Larsson & Athlin (2012)	****
Johansson et al. (2014)	****
Lau et al. (2008)	****
Legault & Ducharme (2009)	****
Mixed methods studies	
Port et al. (2005) [a]	***
Robison et al. (2007)	***
Bramble, Moyle & McAllister (2009) [d]	****
Bramble, Moyle & Shum (2011) [d]	****

Note. Scores vary from *(25%) one criterion met, to **** (100%) all criteria met

[a] related studies (Dementia Care Project, USA)

[b] related studies (Palliative Care Intervention, USA)

[c] related studies

[d] mixed method study reported separately by method; 2009 paper reports qualitative results

home at admission, and this did not change over time (Levy-Storms & Miller-Martinez, 2005). Three studies found types of FI included seeking connection and collaboration with staff, preserving both the continuity of family-resident relationship and the resident's sense of self (Bramble et al., 2009; Edvardsson, Fetherstonhaugh, & Nay, 2010; Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006).

Visitation and frequency of family involvement.

Eight studies including some of those already mentioned explored contact involvement and found that the majority of families remain involved with relatives following placement (Cohen et al., 2014; Dobbs et al., 2005; Gladstone et al., 2006; Grabowski & Mitchell, 2009, Minematsu, 2006; Port et al., 2005; Reinhardt et al., 2015; Zimmerman et al., 2005). Reinhardt, Boerner, and Downes (2015) noted in their correlational study sample description that 47% of families visited relatives at least once per week (N=90) while in a cross sectional study with a large sample (N=400) the finding was 70% (Dobbs et al., 2005). Four correlational studies reported that some families spend seven or more hours per week or over ten visits per month with residents (Cohen et al., 2014; Grabowski & Mitchell, 2009; Minematsu, 2006; Zimmerman et al., 2005). Gladstone, Dupuis, and Wexler's (2006) quantitative study found that after 12 months, 23% of families had more contact with their relative and the average weekly number of family visits had increased to just over two and a half times per week. Port et al. (2005) compared visits by type of residential facility and found there to be no difference in frequency of visitation.

Table 4

Types of family involvement activities

Activities undertaken (potential roles/purpose)

- Visit and Contact (Cohen; Dobbs; Gladstone; Grabowski; Helgesen; Minematsu; Port; Reinhardt; Zimmerman)
- Personal (ADL) support (Gladstone; Levy; Port)
- Instrumental (IADL) support (Lau; Levy; Gladstone; Port)
- Preservative support (Edvardsson; Gladstone; Helgesen; Lau; Port)
  - *Kinship, maintain relationship/ life, connection with past (Edvardsson; Lau; Port)*
  - *Provide link to outside world (Helgesen)*
- Psychosocial/emotional support (Dobbs; Gladstone; Port)
  - *Participate in social activities to encourage resident participation (Dobbs)*
  - *Assess activities (Dobbs)*
- Collaborate and actively develop family-staff partnerships (Caron; Edvardsson; Lau; Reid)
  - *Develop trust (Edvardsson; Reid), pre-existing or blind (Caron)*
  - Understand and promote care home policies
  - *Recognise and accept care home (Lau)*
  - *Make emotional adjustments – identify goals and others' perspectives (Lau)*
  - *Achieve institutional social penetration (Lau)*
    - *with self disclosure (Lau)*
  - *Seek personalised relationship with staff (Caron)*
- Advocate (Bramble; Helgesen; Legault; Port)
- Be guardian (Grabowski; Helgesen)
- Supervise, influence and direct care (Edvardsson; Reid; Reinhardt; Port)
  - *Participate in EOL discussions (Reinhardt)*
  - *Plan care (Port)*
  - *Make decisions (Port; Reid)*
  - *Receive information about care changes (Reid)*
  - Teach staff / be a resource
    - *Share unique knowledge of resident with staff (Edvardsson)*
- Monitor quality of care (Bramble; Gladstone; Grabowski; Helgesen; Port; Reid)
  - *medical (Port) and physical care (Bramble)*
  - *finances (Port)*
  - *resident adjustment (Gladstone), wellbeing (Port; Reid), comfort and dignity (Helgesen)*
  - *staff (Gladstone)*
- *Evaluate quality of care (Bramble; Lau; Legault; Strang)*
  - *attitude of staff and friendliness (Bramble)*

Note. Italics = refers to a 'new' type or sub type of involvement i.e. a type that was not distinguished ('known) in the paper by Gaugler (2005). With the exception of 'new' types of family involvement, subtypes within Personal, Instrumental, Preservative and Psychosocial support are well known and have not been displayed in order to save space. References to Bramble refers to Bramble, Moyle & McAllister, 2009 and references to Reinhardt refers to Reinhardt, Boerner & Downes, 2015 (multi-paper authors included in this review).

2. *Which factors influence family involvement with care homes?*

Factors that influence FI are many, varied and interwoven across the agents involved; the care home, its staff, the resident and the family (Table 5). Influences do not occur in isolation. They contribute to the dynamic nature of family involvement and the unique inter-family and intra-family preferences of and about involvement. Fourteen out of the 26 papers in this review considered factors that influence involvement and a slight majority highlighted at least one factor that either aided involvement or resulted in increased contact. Of the ten qualitative, two longitudinal and two cross-sectional studies, one achieved a MMAT score of * so was excluded from these results.

Along with the result of family evaluation of care, the important factors influencing FI found across nine studies were; family trust in staff, family desire for integration into the care team and their wish for development of close, personal, family-staff relationships (Caron et al., 2005; Gladstone et al., 2006; Helgesen et al., 2012; Johansson, Ruzin, Graneheim & Lindgren, 2014; Lau, Shyu, Lin, & Yang, 2008; Legault & Ducharme, 2009; Majerovitz, Mollott. & Rudder, 2009; Reid & Chappell, 2015; Port et al., 2005). Trust facilitated contact and, both enabled and excused family participation in decision making (Caron et al., 2005; Reid & Chappell, 2015). A lack of trust and a care evaluation of poor were linked with increased supervision and advocacy (Helgesen et al., 2012; Legault, 2009; Strang et al., 2006) and hindered positive family-staff relationships (Lau et al., 2008; Majerovitz et al., 2009).

Desire for both participation and recognition as a care partner increased involvement (Caron et al., 2005; Johanssen et al., 2014; Port, 2005) while poor, unstructured family-staff communication inhibited participation (Bramble et al., 2009; Stirling et al., 2014). Changes in resident adjustment and mood could both motivate involvement or result in fewer visits (Gladstone et al., 2006; Helgesen, et al., 2012).

Table 5

Agents and factors that influence Family Involvement (FI) with care homes following placement of a relative with dementia

	Influence of factor on family involvement with the care home				
Agent (Care Home/Staff or Resident or Family) and Influential factor	Overall		On visits and contact		
	Assists or stimulates	Prevents or discourages	Increases	Decreases	No influence
Care Home/Staff					
Family oriented policies; Encouraged contact with families and family visits FI opportunities and assistance offered	Gladstone, Reid, Port (e.g. organisational openness)	Bramble (e.g. when not offered)		Gladstone (e.g. when FI encouraged)	
Staff levels, work patterns, inter-staff communication		Majerovitz, Bramble (e.g. understaffing)			
Staff communication with families (frequency/ structure/ type)	Port, Majerovitz, Bramble Stirling (e.g. meeting regime)	Caron, Bramble, Stirling Majerovitz (e.g. if limited or critical)			
Quality of relationship with family	Caron, Johanssen, Bramble, Legault (e.g. if personalised)	Majerovitz (e.g. staff unwilling to hear negative feedback)			
Type of care home, physical environment and geographical location				Port (e.g. when spec dementia services)	Port (e.g. of facility type on visit frequency)
Resident					
Length of placement					Gladstone, Legault
Increase in dementia severity/ symptoms**	Helgesen			Gladstone, Helgesen (e.g. if unresponsiveness ensues)	Cohen (e.g. on visit frequency)
Adjustment and mood	Helgesen			Gladstone, Helgesen (e.g. if resident adapted)	
Physical and overall health	Helgesen		Gladstone (e.g. if deterioration)		
Family					
Feeling recognised as a care partner	Johanssen				
Wish to participate/ collaborate and respect staff	Legault, Bramble, Helgesen (e.g. to learn new skills)	Majerovitz, Helgesen (e.g. difficult visits)			

Table 5 *(Continued)*

	Influence of factor on family involvement				
Agent (Care Home/Staff or Resident or Family) and Influential factor	Involvement with care home overall		Visits and contact with care home		
	Assists or stimulates	Prevents or discourages	Increases	Decreases	No influence
Family (continued)					
Role perception	Gladstone, Helgesen (e.g. ‘caregiver’ led to more active involvement	Gladstone, Helgesen (e.g. ‘visitor’ led to less active involvement)			
Perceived opportunities for involvement	Reid				
Perceived quality and satisfaction with care	Lau, Legault, Bramble Helgesen (e.g. good eval led to better collaboration)			Helgesen, Gladstone (e.g. passive if good eval, less monitoring)	
Trust in staff	Reid	Caron (e.g. pre-existing trust led to lower participation)	Legault, Helgesen (e.g. low trust led to heightened supervision)		
Beliefs about dementia care	Lau (e.g. realistic expectations)	Majerovitz (e.g. perceive staff not doing best)			
Beliefs and Values/ Sense of purpose	Caron, Gladstone, Strang (e.g. keep continuity)				
Closeness to resident	Johanssen, Helgesen, Strang				Strang
Additional intra-family involvement				Gladstone	
Perceived own incompetence		Caron (e.g. blind trust in staff)			
Social network	Johanssen, Bramble				
Communication style	Lau, Legault				
Emotional difficulty (control, sadness)	Majerovitz, Strang			Gladstone, Bramble	
Guilt**	Johanssen, Strang, Majerovitz			Gladstone	
Competing demands				Gladstone	

Note. ** Contradictory findings. Spec= Specialist; Eval=Evaluation

Involvement in resident personal care and monitoring of staff reduced as confidence in care delivery increased though visits increased as a resident's health deteriorated (Gladstone et al., 2006; Helgesen et al., 2012). In contrast, other studies found no difference in visit frequency as a function of dementia severity (Cohen et al., 2014) or length of placement (Gladstone et al., 2006; Legault & Ducharme, 2009).

Summary

In response to the first two research questions, a wide array of types of FI and factors that influence FI following placement of a relative with dementia have been identified. There is a complex, multidimensional and evolving interplay across family assigned roles, the nature of family and staff FI preferences, and interactions between; the care home (environment, culture, policies and systems), the three parties (families, residents and staff) and the activities in which families participate.

3. How have care homes promoted family involvement and which interventions have been trialled?

Six studies looked at interventions designed to promote or improve at least one aspect of FI. The studies were from three different countries (USA, UK and Australia) and included five separate interventions. The Jablonski, Reed and Maas (2005) study achieved a MMAT score of ** and is not included here though this is mainly due to its single focus on resident outcomes which is covered in the next section. With so few studies to draw on it is difficult to make conclusions in agreement or otherwise with previous reviews.

Robison et al. (2007) clustered randomised control trial (CRCT) found that a Partner in Caregiving (PIC) intervention was effective for improving family-staff communication and increasing spousal or same generation contact. Both of these results were sustained at a six month follow up, however, no significant change in staff reported conflict was found. Despite this, the care homes were also found to have increased the number of programmes offered to families. Reinhardt, Chichin, Posner, and Kassabian (2014) randomised control trial (RCT) with a palliative care conversation intervention found families added end-of-life care decisions to resident records and family satisfaction with care increased and remained so at six months follow up. Another CRCT by Bramble, Moyle, and Shum (2011) found the Family Involvement in Care (FIC) intervention to significantly improve family knowledge of dementia while family satisfaction with staff consideration and management effectiveness decreased.

Stirling et al. (2014) study evaluating a Dementia and Dying discussion tool found that all care homes in their study had established processes and policies for involving families in the event that a resident's health significantly deteriorated. However, participants also advised communication and information provision could be improved. After trialling Dementia and Dying, families perceived that the tool promoted a new, positive, and transparent communication style as well as improved family-staff relationships. Both family and staff confidence in talking about the course of dementia improved and overall engagement increased (Stirling et al., 2014).

Aveyard and Davies (2006) study conducted over two years, evaluated an action group intervention that was based on relationship-centred care and a senses framework. Family and staff learnt to value each other and develop a powerful voice for change. Results also included improved family-staff partnerships, greater shared understanding and better communication. Families reported a sense of having a place and role in the care home, improved opportunities to support staff and a new purpose in visiting. Staff reported appreciation of support, recognition and positive feedback from families. In contrast, barriers to involvement included staff work patterns, time consuming written communication and environmental concerns (Aveyard & Davies, 2006).

4. Does family involvement with care homes have a positive effect on residents' behavioural and psychological symptoms (BPSD) and quality of life?

Of the 26 papers, eight involved studies that measured outcomes for residents in relation to family contact involvement or FI interventions. Of the eight, two achieved a MMAT score of ** or below, Jablonski et al. (2005) and Minematsu (2006). This variation in quality of the evidence available may have contributed to the inconsistency of the review findings.

The CRCT and RCT investigating different FI interventions as described earlier in this review, contrasted in outcomes of BPSD for residents at six-month follow-up. While Robison et al. (2007) found resident behaviours improved Reinhardt et al. (2014) found no significant change in symptom management. This later finding was echoed in Jablonski et al. (2005) CRCT undertaken over nine months where no significant effect of the FIC intervention was found for resident self-care ability, inappropriate behaviour or agitation.

Minematsu (2006) correlational longitudinal study found family visit frequency was associated with a reduction in BPSD for residents with moderate dementia and, that a positive change in BPSD was greater for residents receiving a monthly average of up to 10 visits when compared to residents receiving more than ten visits in a month. Two further correlational longitudinal studies and one cross sectional study found FI to be related to positive quality of life benefits for residents (Chappell et al., 2014; Dobbs et al., 2005; Zimmerman et al., 2005). Chappell, Kadlec and Reid (2014) found FI was associated to higher resident quality of life in activity participation however it was not a significant predictor of change in resident social skills.

Grabowski and Mitchell (2009) found no significant differences in quality of end-of-life care outcomes if residents were visited for none or between one to seven hours per week. Residents who were visited by family for over seven hours per week experienced significantly worse quality of care in five out of eight end-of-life care outcomes. While this study did not directly measure resident quality of life it has been included here as quality of care is a core contributor to quality of life (Banerjee, Willis, Graham, & Gurland, 2010).

Summary

In response to the final two research questions, few interventions have been developed to promote family involvement within care homes following placement of a relative with dementia. Of the interventions trialled, all were found to yield positive results. However, overall FI intervention influence on residents' BPSD and quality of life was mixed.

Discussion

What do we know now that we did not know ten years ago?

Types of activities.

This mixed studies review has identified that types of FI activities are broader in range than originally identified and differences between types are now distinct and better understood. New types and subtypes of involvement have been highlighted in Table 4 alongside the eleven overarching types of non-dementia specific FI that were understood a decade ago. Emphasis has moved beyond personal, instrumental, preservative and socio-emotional care activities (Gladstone et al., 2006) to the regularly featured involvement types of advocacy and evaluation of care.

Advocacy did not feature prominently a decade ago (MacDonald, 2005). In contrast, in this review, being an advocate, spokesperson and guardian were repeatedly identified as important involvement activities and roles (Bramble et al., 2009; Helgesen et al., 2012; Legault & Ducharme, 2009). This concurred with recent literature (Graneheim et al., 2014; Petriwskyj et al., 2014) and a distinction was made between active advocate involvement and the more passive visitor involvement (Helgesen et al., 2012).

A positive family-staff relationship appears to no longer be satisfactory for many families. Within a new landscape of care partnerships, families now seek personalised, meaningful relationships with staff and recognition of their role as a care partner (Aveyard & Davies, 2006; Bramble et al., 2009; Caron et al., 2005; Lau et al., 2008). Consistent with other reviews (Gaugler, 2005; Petriwksyj et al., 2014) the majority of families wish to remain involved and become more involved with care homes following relative placement.

Influences on involvement.

This review confirmed that the array of factors already known to influence FI with care homes also pertain to FI following placement of a relative with dementia. Additional variables that prohibit or provide motivation for involvement were identified. Similar to other findings (Petriwskyj et al., 2014) understaffing and unhelpful staff working patterns hindered involvement (Bramble et al., 2009; Majerovitz et al., 2009) as did competing demands on families (Gladstone et al., 2006). Also akin to recent literature (Graneheim et al., 2014; Petriwskyj et al., 2014; Ward-Griffin, Bol, Hay, & Dashnay, 2003) quality of staff-family relationships (Bramble et al., 2009), staff offers of involvement opportunities and assistance (Reid & Chappell, 2015) as well as families' perception that they are recognised as a care partner (Johannsen et al., 2014) with unique knowledge of the resident, all facilitate involvement.

Involvement interventions.

Consistent with earlier reviews (Gaugler, 2005; Petriwskyj et al., 2014) there is evidence that a PIC intervention adapted for dementia settings produces positive benefits for families and staff. The FIC intervention also appeared to translate well to care homes in a country (Australia) beyond the USA. FI interventions about end-of-life decision making were well received and improved communication. However, while these findings are encouraging they are based on only a handful of studies.

Resident outcomes and family involvement.

Some findings in this review challenge the assertion that FI leads to improved quality of life and quality of care for residents (Gaugler, 2005). Instead, FI and involvement interventions may not universally benefit residents even when families and staff report increased contact, improved family-staff collaboration or satisfaction with care (Jablonski et al., 2005; Petriwskyj et al., 2014; Reinhardt et al., 2014). Similarly, to Kidder and Smith's (2006) findings, high family contact frequency was linked to worse outcomes for residents and lower quality of care. There may be an optimum level of family contact, no more than ten visits per month or seven hours per week, that enables positive BPSD and quality of life outcomes for residents with dementia (Grabowski & Mitchell, 2009; Minematsu, 2006).

The small number of studies, variation in findings and study quality, small samples and selection biases mean a reliable conclusion cannot be drawn about the positive changes in BPSD, increased participation in activities and positive association with quality of life that were found in half of the studies considering resident outcomes. Further research using multiple informants is required to confirm visit and contact related results as staff report lower family contact frequency than families report (Cohen et al., 2014) and most visit analyses have continued to use a single informant (Dobbs et al., 2005; Grabowski & Mitchell, 2009; Minematsu, 2006; Zimmerman et al., 2005).

Have family-staff partnerships evolved and increased in transparency?

Transparency as a distinct construct was not specifically examined in any of the included studies. Legault and Ducharme (2009) study investigating advocacy found that staff transparency about incidents was critical in the development of trust in family–staff relationships. This finding is harmonious with the UK's duty of candour regulation which aims to ensure an open, honest and transparent culture in care provision settings (CQC, 2015).

Robison et al. (2007) collected data on recorded incidents involving families and the receipt of complaints from families though it did not report the frequency results. Instead, the collective positive feedback from care home management about the PIC-SCU intervention was reported and indicated a sense of improvement in incident and complaint occurrence and management. Cohen et al. (2014) suggested increased transparency in roles and involvement would promote family-staff partnership.

Factors that negatively influence FI included inadequate information provision and staff communication, involvement not always being encouraged, family perceptions that staff are not doing their best and lack of respect for or blind trust in staff. All of these are likely to hinder transparency, advocacy and relationships (Petriwskyj et al., 2014). This review reflects existing evidence (Marquis, Freegard, & Hoogland, 2004; Petriwskyj et al., 2014) that trust and openness are important factors in involvement and indicates there is a growing emphasis on open family-staff relationships and care home encouragement of involvement through policies, processes, interventions and the provision of opportunities for and assistance with involvement.

Have Gaugler's (2005) recommendations for research been adopted?

Recommendations for refinement of the evidence base have been partially met. Ten of the studies included in this review had longitudinal designs. Eight studies included both FI measures or interventions as well as resident outcome measures, though links between these were not always significant. A small number of interventions have been evaluated and have primarily used clustered site randomisation in their methodology which is appropriate when working with care homes (Donner & Klar, 2000).

Strengths and Limitations

The search strategy and search terms were entered into three databases. Extensive hand-searches were completed to ensure search strategy bias was minimised and as a result thirteen additional papers were included. Of the reviews that have primarily been consulted for comparison (Graneheim et al., 2014; Petriwskyj et al., 2014 qualitative and quantitative papers) five of the 121 papers included in their references matched studies selected for this review. To limit reporting bias, findings that corroborate and contrast in evidence to findings in this review have only been described when alternative papers within the comparison reviews were cited.

The MMAT quality appraisal tool used in this review developed by Pluye et al. (2011) is an efficient new tool that continues to undergo development. It has been used worldwide for at least 50 systematic mixed studies reviews (Pluye, Hong, & Vedel, 2013). The MMAT has accrued positive evaluation and evidence of content validity and reliability (Crowe & Sheppard, 2011; Pace et al., 2012) though further improvements are recommended (Souto et al., 2015). Caution was exercised by selecting six papers that included studies of various designs to be appraised with the Kmet, Lee, and Cook (2004) appraisal tools and for comparison with MMAT scores. The results indicated that there were no obvious differences in appraisal between the two tools such that a paper with a low Kmet et al. (2004) score was also found to have a low MMAT rating.

The majority of studies investigated a single specific topic of participation or included involvement measures and did not directly explore involvement types or influences. Therefore, in addition to caregiver stressors that are not the focus of this review, the identified types of and influences on involvement, while numerous, may be incomplete. However, this is the only known systematic review to consider types and influences of FI exclusively in relation to dementia therefore the author has confidence that the tables displayed are comprehensive.

Implications for clinical practice

Benefits.

Family roles and involvement are often dynamic and ambiguous (Graneheim et al., 2014; Petriwskyj et al., 2014). Expectations for involvement differ for each family (Caron et al., 2005; Reid & Chappell, 2015) and this adds more complexity to post-placement FI. There are likely to be key benefits for staff and families, if at the outset of placement, staff share with families that involvement differs for each family according to family preferences.

Initiation of positive staff-family relationships are likely to take place if staff enquire about family expectations and hopes for involvement and provide information about how FI is promoted within the care home. This approach will help both families and staff to; build an individualised family profile of involvement that can evolve over time, avoid ambiguities about roles and types of involvement each party will participate in, learn about the factors that immediately influence a specific family's involvement and model a collaborative, transparent relationship.

Involvement as routine care.

FI interventions may be viewed as an extra demand, time consuming and difficult to implement by some staff and families (Maas, Kelley, Park, & Specht, 2002). In the PIC-SCU study researchers proposed that more would need to be done to encourage family participation (Robison et al., 2007). Staff shortages, low staff to resident ratios and low pay can be barriers to staff participation in something that they perceive as extra (Maas et al., 2002). For families, staff and residents to gain the benefits available, FI interventions need to become a routine part of care home policy and practice such that they move from interventions to best practice.

Open access to involvement guides.

Additionally, trials that rely on a research team to deliver an intervention mean interventions are not tested in the most realistic conditions by the very staff that eventually may promote them. This can lead to unrepresentative research results (Leichsenring, 2004) and make decisions about wider implementation of interventions more difficult for care home managers. Three of the involvement intervention guides from studies in this review were easily accessible though one required a request to be sent to the authors. Detailed theoretical frameworks were available for a further intervention while another appeared to be limited to the description within an empirical paper. Care home promotion of involvement continues to be sporadic and often basic (Ampe, Sevenants, Smets, Declercq, & Van Audenhove, 2016) therefore open access to detailed guides would encourage wider replication of the FI interventions and facilitate evidence-based best practice in care.

Revised definition.

Finally, one clinical implication from the findings in this review is that the commonly used description of FI, that of a multidimensional construct that entails visiting, socio-emotional care, advocacy and the provision of personal care (Gaugler, 2005; Reid, et al., 2007) could be updated. Instead, FI may be more accurately described as a multidimensional construct that can entail visiting, advocacy, supervising, monitoring and evaluating care, development of care partnerships and foundation care (personal, instrumental, preservative and psychosocial). This description aims to better reflect the range and types of involvement that are important to families.

Future research

Resident outcomes.

Few studies have explored the links between FI and resident outcomes. To expand the evidence regarding contact involvement and resident BPSD and quality of life, future research needs to investigate links between an array of involvement types such as personalisation of family-staff relationships, teamwork, family-staff discussions and resident outcomes. This would provide more clarity about the effect the shift in emphasis to partnerships and evaluation of care and away from foundation care, is having on residents. We also lack substantial evidence for how the absence of family or existing yet uninvolved family effect residents with dementia, family and staff outcomes. Do staff prefer working with residents who do not have family or whose families are uninvolved?

UK and European research.

This review indicates that UK based research in FI following placement of a relative with dementia is currently under represented. Care culture differs across localities (Killet et al., 2016) therefore completing studies in the UK and Europe provide some insight of cultural influences and address the evidence imbalance. Further testing of PIC, FIC and other FI interventions is also necessary for robust evaluation (Craig et al., 2013). Replication will help determine if the trend of positive outcomes for families and staff and weaker though still positive trend for resident' outcomes is universal or potentially interacting with other factors such as influences on FI, organisation culture or individual resident differences.

No and minimal involvement.

Uninvolved and barely involved families rarely featured in the study samples. While these groups may be hard to reach or be unwilling to be involved in research, exclusions and self-selected samples can lead to bias and may be hindering a complete understanding (Craig et al., 2013). Reid and Chappell (2015) looked at whether families were involved in the types of activities they perceived to be most important and found 20% to 30% were not getting what they wanted. In a conventional staff-family relationship, families are not specifically encouraged by staff to become involved in care (Ward-Griffin et al., 2003). Therefore, research with families, who have no or minimal involvement post-placement of a relative with dementia, would ensure we understand if families have been discouraged from participation, have mismatched expectations about how they might participate, and the opportunities to do so or if there are other unknown influences preventing involvement.

Intervention replication.

Across the entire set of study designs and reporting there were weaknesses which may have inflated the risk of bias in results. Three studies used cluster randomisation designs (Bramble et al., 2011; Jablonski et al., 2005; Robison et al., 2007) that are appropriate when working with care homes to avoid contamination between experimental and comparison participants. However, the studies varied in their consideration of and control for clustering effects so confounding by site and intra-cluster correlation effects may have effected their results (Donner & Klar, 2000). Small samples of two or fewer care homes and inconsistent variance and effect size reporting were also problematic. In qualitative studies the inclusion of an atypical, non-country representative care home and the lack of result verification processes were design disadvantages. The evidence would benefit from further development, testing and wider country replication of FI interventions particularly those that target more than one domain of FI.

Standard measures and reporting.

Many studies in the review were diverse in their focus and heavily reliant on family self-report of involvement. The inconsistent measures and reporting of visit frequency across the studies make it difficult to draw a conclusion about how often most families visit and have post-placement contact with residents with dementia. The studies informing the breadth of influences on FI have predominantly, unsurprisingly, originated from qualitative studies and while they tend to be rich in data, eight of the papers referred to samples with three or fewer care homes. To better understand the associations and interactions between specific factors that influence FI, further studies with large sample sizes and mixed method designs would be appropriate.

Optimum levels of involvement.

The literature would be enhanced by dementia specific research that explores in detail, the conditions and circumstances in which high levels of FI result in negative psychosocial, quality of life and care outcomes for residents. Development and evaluation of effective methods of communicating this evidence to families and negotiating a new involvement profile while maintaining a positive, collaborative, partnership approach would also be necessary.

Conclusions

Sound progress has been made in our understanding of FI with care homes following placement of a relative with dementia over the last ten years. Nevertheless, many findings are under corroborated, raise further questions for refinement and gaps in the evidence remain. This review provides greater clarity about Gladstone, Dupuis, and Wexler’s (2006) idea that families provide new types of care, such as evaluating care quality, emphasise one type of ongoing care over another type, such as emotional support over personal care or express ongoing care in new ways, such as investing time in creating personalised relationships with staff.

FI is yet to be fully embedded in care home practice and there may be a dilemma in developing the FI evidence base. To convince staff to embrace FI as part of standard practice, more worldwide research is required to substantiate the positive links found between FI interventions and resident outcomes, and to identify any over-involvement effects. To produce results that are meaningful to staff namely where real life conditions involving staff delivery of FI interventions has been emulated, staff would first have to be attracted to participating in research to develop the evidence base. To mitigate the dilemma, it is critical that FI interventions are ‘light touch’ and easily integrated into care practice so that they attract staff to participate in trials and adopt successful FI interventions as standard practice.

Overall, this review contributes to the evidence base for dementia research by providing a synthesis of the literature concerning family involvement with care homes following placement of a resident with dementia.

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- Denotes a paper included in the systematic review

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Part II: Empirical Paper

Healthy adjustment for new residents with dementia using SettleIN: a feasibility study with staff in UK care homes.

Abstract

Aims: This study aimed to develop and evaluate SettleIN, a staff led programme about healthy adjustment for people with dementia following care home placement. The main foci were intervention feasibility and the impact of the programme on resident quality of life and mood.

Method: A manualised intervention was developed through consultation with forty-seven experts by profession (n= 30) and family care (n=17). The effects of the intervention were then evaluated for thirteen recently admitted residents with dementia and 24 staff recruited from six UK care homes. Staff were trained in SettleIN. A mixed methods design was used. Outcomes were measured at baseline, intervention completion and at a four-week follow up. Staff interviews (n=6), staff field notes (n=4) and researcher field notes (n=11) were collected and analysed.

Results: Uptake of SettleIN varied between and within care homes. When implemented, staff emphasised that SettleIN was easily integrated into care practice and better than care-as-usual. However, SettleIN may not be suitable for all residents. A high attrition rate and inconclusive mixed model analysis meant there was a lack of support for the positive outcomes found for some residents and other residents may have had less benefit. Partial results were only obtained from four participants due to attrition arising from death or hospitalisation (n=5) or lack of uptake (n=4) or missing scale responses (2). Intervention feasibility issues were dominated by a lack of staff time and delivery of some components was hampered by a dependency on families.

Conclusion: SettleIN is acceptable to a wide range of stakeholders. However, it does not appear to be feasible in its current form and improvements are recommended. A second pilot phase is required, which will address the reasons for the high attrition rate in this study and amend the methodology accordingly.

Introduction

There are 46.8 million people worldwide living with dementia and this number is predicted to double every 20 years for the foreseeable future (Alzheimer's Disease International [ADI], 2015). Of these people, approximately one third to one half in high income countries, and approximately six percent of those in low and middle income countries are cared for in long-term care facilities (Prince et al., 2013). The number of people with dementia in care homes in England alone are conservatively estimated to rise to 390,000 in 2031 (Comas-Herrera et al., 2011).

Admission into a care home for people with dementia has been linked with both positive and negative psychological outcomes for both the resident and their carers (Bekhet, Zauszniewski, & Wykle, 2008; Gaugler, Pot and Zarit, 2007; Schulz et al., 2004; Sury, Burns & Brodaty, 2013). Adjustment to life in a care home can take between two to four weeks or as long as six months (Ellis, 2010; Hodgson, Freedman, Granger & Erno, 2004). Whilst some people with dementia adjust spontaneously, many never adjust at all or adjustment is complex and linked to cognitive and behavioural decline (Kydd, 2001; Wilson, 2008). Therefore, support for healthy adjustment is needed.

Definition of Adjustment

Smith and Crome (2000) defined transition or relocation to a care home as a multi-phased process that involves a decision-making stage, a moving stage, and an initial adjustment stage. This initial adjustment stage is indicative of 'settling in' (Prager,1986). In this context, transition is defined as the process or period of changing from one state or condition to another while adjustment refers to the process of adapting or becoming used to a new situation (Oxford Dictionaries, 2016).

Relevant Literature

A systematic review of the literature between 1990 and 2011 by Sury, Burns, and Brodaty (2013) identified a range of factors that influence transition outcomes for people with dementia after placement in a care home such as a loss of familiar people and unmet needs. The review also highlighted problems associated with poor adjustment such as depression, agitation, worse physical health, social withdrawal and decreased cognition. Furthermore, these problems have been associated with poorer quality of life for residents (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013). Successful adjustment is facilitated by a person centred approach comprising of orientation procedures, buddy systems and input into decision-making (Sury et al., 2013).

In the first six months after care home placement, people with dementia adapt by placing emphasis on settling in, fitting in and finding meaning in order to create a home and integrate the relocation within their overall life history and self-identity (Aminzadeh, Molnar, Dalziel, & Garcia, 2013). Person centred advanced planning and preparation, active engagement of family caregivers and highly responsive care environments help to prevent adverse reactions to relocation (Aminzadeh et al., 2013).

Since 2011 one study pertaining to an intervention targeting the early period of care home residency has been published. The intervention aimed to improve the transfer of people with dementia with behavioural problems. The study found that a visit to care home staff by a community psychiatric nurse with prior knowledge of the resident, to provide advice about working with behaviour that was challenging was experienced as too late, at six weeks after admission; staff had already conferred with their own multidisciplinary team for support (Van Mierlo et al., 2015).

Non-dementia specific studies have found similar difficulties such as depression and anger to be associated with poor adjustment following care home placement and similar factors to influence adjustment outcomes (Brownie, Horstmanshof, & Garbutt, 2014). For instance, identity preservation and flexible application of care home policies are essential for new resident comfort (Cooney, 2012; Sussman & Dupuis, 2014). Furthermore, predictors of adjustment include resident perceived self efficacy, health, beliefs about care homes and emotional support from staff and other residents (Lee, 2010).

Wider dementia related studies have demonstrated the benefits of maximising independent living (Knapp et al., Alzheimer's Society, 2007), and the effectiveness of non-pharmacological interventions for improving care home resident quality of life, well-being and BPSD (Cooper et al., 2012; Lawrence, Fossey, Ballard, Moniz Cook, & Murray., 2012; Spector et al., 2003; Teri, Logsdon, Uomoto, & Mccurry, 1997). Studies have yet to focus on interventions that target the initial stage of residency – the care home adjustment phase.

Length of Stay and Pre-admission

While the specific length of stay figures relating to dementia remain unclear, in the UK, the median period of a care home stay is 15 months and approximately 27% of people reside for more than three years (Forder & Fernandez, 2011). Therefore, focus on the adjustment period and development of interventions to enhance the transition for residents into care homes and improve their and their families' subsequent quality of lives is warranted (Sury et al., 2013). Additionally, adaptation to care home placement is further complicated when recommended pre-admission activities, such as resident involvement in decision making and orientation visits, are not always possible as admission may have taken place quickly. This may be due to pre-admission hospitalisation, dementia progression or increased carer burden. New residents in this scenario are likely to need additional support with adjustment and interventions to support adaptation to living in a care home would need to address any absence of pre-admission best practice.

Theory

The theory of personal constructs (Kelly 1955, 1991) and the process of transition (Fisher 1999, 2000) can inform adjustment (Ellis, 2010) and therefore inform, adjustment to care interventions. Ellis (2010) posited that residents and carers can experience anxiety, fear of the future and invalidation as they undergo relocation transition. Furthermore, for some residents, poor adjustment to care home placement may be due to a resident's perception of there being no benefit to living in a care home or perceived incongruence between their new residence and their personal goals, values and sense of identity. Therefore, an intervention that promotes healthy adjustment would need to help new residents with dementia and their carers to identify benefits in care home residence, ensure staff know of and validate the new residents' personal goals, values and sense of identity as well as promote opportunities for the new resident to express these within the care home environment.

The Current Study

In response to the UK National Dementia strategy to support people to 'live well' with dementia (Department of Health, 2011) and the Alzheimer's Disease International's recommendation that systems and services be made simple, seamless, transparent and accessible in care home settings (Prince, Prina, & Guerchet, ADI, 2013), this study aimed to validate and complete a feasibility study of SettleIN. SettleIN is an intervention focussed on promoting healthy adjustment, in the initial stage of residency, for people with dementia following placement into a care home. The SettleIN intervention attempts to bridge the gap between support for independent living and support for end of life care and thereby complement the full cycle of care for people with dementia.

Research Aims

1. To develop the SettleIN intervention through a literature review and consultation with academic, clinical and family experts by profession and experience.
2. To evaluate the feasibility and preliminary outcomes of SettleIN.

Research Hypotheses

1. SettleIN will be feasible for care home staff to implement and deliver.
2. People with dementia will experience and retain an improved mood and higher quality of life after having completed SettleIN.
3. Family carers will experience higher satisfaction with care after their relative has completed SettleIN.

Method

A two phase, partly parallel design based on the Medical Research Council's framework was used to develop and evaluate the feasibility of the SettleIN intervention (Moore et al., 2015).

Phase I: Intervention Development

The SettleIN programme was created by reviewing the 15 positive and negative factors known to influence adjustment (Sury et al., 2013) and arranging them into six groups, according to relatedness and core elements of adjustment theory (Ellis, 2010). A multipart activity or subset of activities for single or repeated use was designed for each group and to address the adjustment factors it contained. After supervisor review, the activities were simplified and reduced in timescale and groups were condensed into four modules named *Orientation, Lifestyle, Family & Friends* and *Identity*.

Subsequently, the modules were combined to form the core of the programme named *Healthy Adjustment*. A brief *Needs Assessment* section was added to the beginning of the programme to ensure that any needs of the resident that may prevent them from completing the SettleIN activities (such as a missing hearing aid) were identified and addressed. A *Future Planning* section was added to the end of the programme to facilitate a plan for maintenance of any positive SettleIN outcomes for residents after programme completion. A colourful and appealing manual was created for SettleIN to help it stand out amongst other care home paperwork. The manual introduction included details of the programme values, the theoretical underpinning of the intervention and information about adjustment in the form of two, one-page information sheets specifically for a resident or a family.

Stakeholder consultation.

Design. Consultation was completed with a range of clinical, academic and family stakeholders during June to November 2015 and all were identified through personal contacts of the researcher. The purpose of the consultation was to gain insight into the acceptability of the activities included in SettleIN for use with people with dementia and to ensure the intervention materials were easy to understand and feasible for staff to use. A questionnaire based discussion guide (see Table 1 and Appendix B) was developed prior to the consultations. The questionnaire included open questions designed to both promote discussion about the aims, content, language and format of SettleIN and closed questions to allow for specific responses regarding the programme acceptability and feasibility.

Procedure. The consultations were all conducted by the lead researcher alone. They varied in nature from; in person, with an individual or a small group with up to four stakeholders, or remotely via telephone with an individual following a manual having been distributed for review. Focus groups were also held with a London based community memory service team (n=12) and a non-London based

Alzheimer’s Society Carer Group (n=14). Each consultation lasted approximately sixty minutes and were either recorded digitally or as notes taken by the lead researcher. During each in person session the lead researcher provided an overview of the programme and invited the stakeholders to appraise the documentation. An interactive semi-structured discussion followed based on the points of interest outlined in Table 1. Stakeholders provided feedback to the lead researcher informally or via the questionnaire using paper, email or verbal format.

Analysis. Descriptive statistics summarising the individual demographic and clinical characteristics of participating stakeholders are reported along with the results. The questionnaire text responses and independent feedback were made anonymous and imported into NVivo, version 11 (QSR International, 2015). A thematic analysis was then completed (please see the phase II methods section for details of the thematic analysis approach used here and in the feasibility study).

Results of stakeholder consultation

Forty-seven stakeholders were consulted and their demographic details are displayed in Table 2. Thirty-four of the 47 completed a questionnaire about SettleIN. The results are presented in Table 3. The majority indicated that SettleIN was completely appropriate (68%), realistic (79%) and anticipated that delivery of SettleIN within care homes would be feasible (97%, n=28).

The qualitative results were informed by; one transcript from the session with the Alzheimer’s Society Carer’s group, notes taken during the session with the memory services team, responses to open questions from 34 completed questionnaires, notes taken during six individual interviews and 11 small group sessions, and data from three emails containing feedback. Themes derived from the data during the inductive thematic analysis are displayed in Table 4 and

Table 1

Discussion guide and points of interest

Themes	Points of interest
Overall	
	Appropriate for people with dementia
	Realistic for people with dementia
	Change required for more appropriate/realistic
	Like most about SettleIN
	Like least about SettleIN
SettleIN Manual	
Content and Language	How understandable
	Ease of language
	Sections/Pages that need to be clearer
	Adequate terminology and instructions
Module activities	Accuracy of activity duration
	Helpfulness of duration timing
Information Sheets	Appropriate and make sense
	Helpfulness
Feasibility	
	How feasible
	Foreseen obstacles to delivery
	Change required for SettleIN to mitigate obstacles
Role Specific Feedback	
All roles	Acceptable to you
	Change required for more acceptability for your role
	Comparison to care-as-usual
Family	Anything missing from SettleIN (based on your experience)
	Is family involvement clear
Care home management	Willingness to support staff delivery of SettleIN
	Willingness to supervise staff delivery of SettleIN

categorised by acceptability and feasibility. Examples of stakeholder feedback are displayed in Table 5. In summary, the qualitative results from the consultation

Table 2

Demographic characteristics of stakeholder consultants

Characteristic	N (47)	%	Total %
Gender:			
Female	39	83	
Male	8	17	
Age:			
18-24	2	4	
25-34	4	9	
35-44	3	6	
45-54	8	17	
55-64	4	9	
65+	6	13	
Unknown (6 from carer group)	20	43	
Stakeholder consultant role:			
Family carer			36
Full time	7	15	
Part time	4	9	
Unknown	6	13	
Care home staff			21
Manager / Deputy	3	6	
Senior carer / Team leader	2	4	
Care assistant	5	11	
Academic / Academic and Clinician			11
Clinical Psychologist	2	4	
Researcher	1	2	
Psychiatrist	2	4	
Clinician			32
Clinical Psychologist	1	2	
Speech and Language Therapist	1	2	
Occupational Therapist	1	2	
Alzheimer’s Society Support Worker	2	4	
Memory Services Dementia Care Manager	1	2	
Dementia Care Specialist/Nurse	6	13	
Dementia Care Support Worker	3	6	

Note. Percentages are rounded so may not total to exactly 100%

Table 3

Results from the SettleIN stakeholder questionnaire

SettleIN	N *(total responses)*	%
Acceptability:	*(34)*	
Completely inappropriate	0	0
Somewhat inappropriate	0	0
Neither appropriate or inappropriate	3	9
Somewhat appropriate	8	24
Completely appropriate	23	68
Realistic for people with dementia:	*(34)*	
Completely unrealistic	0	0
Somewhat unrealistic	5	16
Neither realistic or unrealistic	2	6
Somewhat realistic	12	35
Completely realistic	15	44
Programme manual overall:	*(31)*	
Very difficult to understand	0	0
Somewhat difficult to understand	1	3
Neither easy or difficult to understand	7	23
Easy to understand	14	45
Very easy to understand	9	29
Manual Language:	*(28)*	
Easy	26	93
Difficult	2	7
Programme delivery feasibility:	*(28)*	
Completely unfeasible	0	0
Slightly unfeasible	0	0
Neither feasible or unfeasible	1	4
Somewhat feasible	15	54
Completely feasible	12	43

Note. Percentages are rounded so may not total to exactly 100%

showed that all stakeholders found the SettleIN programme to be a helpful, useful tool which was likely to aid staff to understand and better meet resident needs.

Several stakeholders mentioned that SettleIN should be part of standard practice and training. SettleIN was considered to be well structured and have comprehensive and appropriate content. Some stakeholders thought SettleIN would be easy to use though others warned of likely barriers to implementation including individual resident differences such as limited communication skills and staff factors such as high turnover and a 'tick-box' attitude. Others highlighted an incongruence between what care homes say they do and what they actually do.

> *'Every home you go to will tell you that's what they do. They don't...so they believe they do it, or they publicise that they do it.'*
> *(Family carer, Alzheimer's Society Carers Group)*

A number of suggestions for manual improvements, additional topics for inclusion and training approaches were collated.

Intervention refinement as a result of consultation

Three main changes were made to improve SettleIN based on guidance provided by the stakeholders alongside minor wording alterations. Following initial consultations and prior to the large group sessions, SettleIN documentation was divided into two; (i) a manual for care home managers that included the theoretical framework and values of the programme and (ii) a workbook for staff that contained the instructions and recording elements of the programme. An overall module planner was added to the workbook at the front of the Healthy Adjustment section so that staff could easily see where they were up to and check off activities completed. Pictures of faces ranging from very unhappy to very happy were added to the needs assessment questions to enable ease of answering for residents. Changes to the planned SettleIN training approach were made which placed greater emphasis on how SettleIN activities might be incorporated into care-as-usual and be adapted for someone who is bed bound. A new manual and workbook were produced in a similar appealing colour and style to that of the original document.

Table 4

Thematic analysis results from the SettleIN stakeholder consultation

1. **SettleIN is acceptable**

Themes and subthemes	N	Themes and subthemes	N
SettleIN is a good concept; SettleIN		**SettleIN will benefit the resident; SettleIN**	
Is appropriate, important and valuable	5	Addresses needs and helps resident feel heard	8
Is helpful, useful and good	15	Includes and treats resident as an individual	5
Is needed, it should be standard in training and practice	7	Helps understanding of the resident and behaviour	9
Is different and better than care-as-usual	2	Will help reduce BPSD	4
Is similar and better than care-as-usual	7	**SettleIN has appropriate content and structure; SettleIN**	
SettleIN involves and will benefit families; SettleIN		Is comprehensive	5
Will help to alleviate stress	6	Has good content and is easy to understand	12
Will help positive family-staff communication and relationship	5	Has strength in it’s format and structure	7
		Has helpful timings for module activities	17

2. **SettleIN is feasible**

Themes and subthemes	N	Themes and subthemes	N
Overall SettleIN is feasible		**Care home systems and staff factors are main barriers**	
Is realistic, practical and easy	10	SettleIN needs to be part of care home systems	2
SettleIN saves time	2	Success would be dependent on staff numbers and ratios	2
SettleIN needs to be monitored and funded		Staff may perceive they have no time for SettleIN	4
SettleIN needs to be monitored and have managerial support	3	Staff turnover would effect delivery and success	4
SettleIN needs funding	2	Staff attitude, quality and performance effect success	4
SettleIN use depends on resident and their communication	5		

Note. BPSD=Behavioural and psychological symptoms of dementia. N=number of stakeholders - not all independent voices in the larger groups were able to be discerned.

Table 5

Examples of quotes from the SettleIN stakeholder consultation

Theme	Quote and Stakeholder Role
SettleIN is a good concept	'There are similar aspects [to care-as-usual] but [SettleIN] would cover and give structure to what is offered between initial assessment and review.'*(Deputy Manager, Care Home)* 'I really hope [SettleIN] becomes a mandatory reality in all care homes in the near future, it would have been of benefit to my family.' (*Speech and Language Therapist)* 'It would be good if SettleIN could be something towards staff training, a bit like a kitemark, care home managers could be proud to have this for their staff.' (*Alzheimer Society Dementia Support Worker)* 'CQC will love it… it will be good for my staff. [SettleIN] will advance day to day practice and help staff be more aware and interactive with residents.' (*Manager, Care Home)*
SettleIN has appropriate content and structure	'The manuals look rich, quite a lot in there. It's a really good idea…The manual seems to be very comprehensive…its like a safety net.' (*Alzheimer Society Dementia Support Worker)* '[SettleIN] puts care according to evidence base standard in a structured framework. This could make it easier for members of staff to follow.' (*Academic and Clinician)*
SettleIN will benefit the resident	'[SettleIN] would make me and my Dad "feel heard".' (*Family carer)* '…[SettleIN] help[s] separate person from behaviour.' (*Manager, Memory Services Team)* '[SettleIN's] very focussed on the needs of the residents.' (*Occupational Therapist)*
SettleIN involves and will benefit families	'[SettleIN] makes you feel their life isn't ending.' (*Family carer)* '[I like] the strength of the connection it will form between care home staff and relatives.' (*Speech and Language Therapist)*
Overall SettleIN is feasible	'SettleIN activities can be done while bathing resident or combing their hair.' (*Head Carer/Team Leader, Care Home)* 'If they are able to communicate then [SettleIN is completely realistic.' (*Care Assistant and Activities Coordinator, Care Home)* 'The whole concept is useful and practical - and novel.' (*Clinical Psychologist)*
SettleIN needs to be monitored and funded	'I don't think the aims are achievable without more funding.' (*Family carer)* '…you should have… the monitoring of [SettleIN] as part of the fundamental path…' (*Family carer)*
SettleIN depends on the resident	'How realistic all depends on the resident especially if someone doesn't have a relative or is unable to communicate or is bed bound.' (*Care Assistant and Activities Coordinator, Care Home)*
CH systems and staff factors are main barriers	'…[SettleIN] is lovely, but you've got to have staff numbers and staff ratio.' (*Family carer)* 'It's got nothing to do with the fees … it has got to do with the quality of the staff…' (*Family carer)*

Phase II: Feasibility Study

Design

The final phase involved a mixed methods within-participant design to investigate the feasibility of SettleIN for staff and to ascertain if any positive outcomes were apparent for new residents with dementia.

Setting

Fifteen UK care homes were contacted during August 2015 to February 2016 after being identified through convenience sampling, a care home network research event and the UK directory of care homes (Care Quality Commission, CQC, 2015). Of these, nine managers were met in person by the lead researcher and invited to participate. Managers from six privately owned care homes across three UK counties accepted. Each care home offered between 30 and 90 beds and had attained essential quality and safety standards ranging from good (N=5) to outstanding (N=1) as defined by the CQC (2015). One care home with a CQC rating of good had no eligible residents at the time the manager granted consent. A change in bed status to ‘for respite’ one month into the duration of the study meant that all incoming residents would be ineligible. Regular contact was maintained with the home throughout the study to monitor changes in bed status.

Recruitment

Participating care home managers contacted 16 new residents and their families or proxies who were likely to be interested in research. Fifteen granted permission for the research team to make further contact. The lead researcher contacted the families and residents to explain the study in more detail, gain consent for resident participation and to confirm resident eligibility. New residents were eligible to participate if they;

- were aged 65 years and older,

- had been in permanent care home residence for less than four weeks,
- had a diagnosis of dementia as defined by the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013)
- had a Functional Assessment Staging Test (FAST; Reisberg, 1987) score of between mild (2) and moderately severe (6e).
- could understand and communicate in English.

One resident did not meet eligibility criteria and another resident was withdrawn by the family shortly after consent was granted due to deterioration in the resident's health. The lead researcher then collected the remaining participants' demographic details from care plan records and baseline measures from the staff lead, family carer and the resident (where possible).

Participants

Thirteen residents from five care homes were included and were all aged 70 years old and above. One resident met the inclusion criteria though preferred to communicate in a language other than English. The SettleIN trained staff lead confirmed she was able to communicate with the resident in his preferred language so the resident remained in the study. Family involvement in the research varied from solely granting consent or completing measures to assisting with intervention activities. Family representatives included seven daughters, three sons, one spouse, one daughter-in-law and one non-related proxy. Family visits appeared to range between daily and once per month with the exception of one family who preferred not to be involved.

Twenty-four staff from the six care homes including the resident participants' key workers were recruited and trained in using SettleIN. All staff who attended training were given a certificate by way of thanks for their participation and those that led a SettleIN programme with a resident were given a gift voucher following study completion.

Ethical Approval

Ethical approval was granted by the Health Research Authority Research Ethics Committee Camden and Kings Cross (Appendix C) and University College London Joint Research Office. Written consent was obtained from all care home managers, staff members and family or proxy representatives of each resident participating in the research (see Appendix D for example information sheets and consent forms). All participants were informed that they could withdraw from the study at any point without having to state any reason and without usual care being effected. All data obtained was made anonymous and identifying information stored separately.

Intervention

Training.

Training varied in nature due to staff availability and the care home setting. The training involved working through the SettleIN workbook, didactic teaching, role plays and question and answer components.

Content and structure.

The SettleIN workbook (see [redacted]) detailed a four-week programme which could be delivered over six weeks depending on staff lead shift pattern and availability. The programme comprised of the three-part framework; *Needs Assessment, Healthy Adjustment* and *Future Planning*. The *Needs Assessment* section was completed with the resident (and their family where possible). It involved gaining the resident's perspective on living in the care home, a brief review of their physical health, and selecting the most relevant modules of healthy adjustment for the resident in order to build their individual programme.

For this trial, all modules were selected for each resident.

The *Healthy Adjustment* section comprised of;

- a module planner that enabled staff to see an overview of the programme, a list of each module and activity and how often and when the activity was to be completed (e.g. one-time, three times in week one, once per week for four weeks),
- four one-page modules named *Orientation, Lifestyle, Family & Friends*, and *Identity*; each detailed up to six activities which were expected to take between ten and 30 minutes to complete,
- templates to capture outcomes from the activities e.g. likes and dislikes,
- templates for recording brief notes about how the resident responded to each activity
- sheets containing question prompts to accompany and facilitate each module.

[redacted] for details of each modules' aims and activities. The final section, *Future Planning*, involved gaining an up to date perspective from the resident about what they think about living in the care home, noting any change and identifying with staff how any positive progress made might be maintained.

Procedure

A SettleIN manual was provided to the care home manager. A SettleIN workbook was provided to the staff participant leading the programme for each recruited resident. The workbook was kept at the care home, alongside each resident's daily care-as-usual progress notes or in an easily accessible location chosen by staff. To aid the start of the programme, and where possible, the *Needs Assessment* was led by the staff participant with in person support from the lead researcher. Thereafter, as soon as possible after the start of each shift, the staff participant checked the SettleIN workbook for instructions about the activities to be completed over each day and week.

Staff worked with the resident (and where involved, the family) to complete one or more activities over the course of a shift, undertaking the activity separately or while completing care-as-usual activities such as helping a resident to dress. Either immediately after completing an activity or later when writing care-as-usual progress notes, staff used the module planner and field note templates within the SettleIN workbook to record which activities had been completed and how the resident had responded. The lead researcher was available to staff for telephone support throughout the duration of the programme and also contacted the care home weekly to check progress and provide assistance.

Post intervention

Four volunteer researchers collected post and follow up intervention measures, alone or in pairs, within a week of SettleIN completion and again four weeks later. Researchers also collected copies of the workbook. Following the completion of the SettleIN delivery period, the lead researcher or one designated volunteer with interview experience, conducted semi structured interviews with staff intervention leads based on a pre-developed guide (see Appendix E).

Measures

Resident measures.

The Functional Assessment Staging Test (FAST, Reisberg, 1987) was chosen to measure the stage of dementia relating to functional deterioration in participants and the score was predominantly ascertained though an interview with the staff. FAST is an empirically supported ordinal scale depicting seven stages ranging from normal function to severe dementia (Sclan & Reisberg, 1992). Stages six and seven are divided into subscales and generate 16 possible ratings. Moderately severe dementia where difficulty dressing, bathing and a person may be incontinent is indicated at stage 6a and above.

The Quality of Life in Alzheimer's Disease (QOL-AD, Logsdon, Gibbons, McCurry, & Teri, 1999) rates the quality of life in persons with dementia and Alzheimer's disease. It is a brief, 13-item self or proxy measure that uses a four point likert scale (where 1 = poor up to 4 = excellent) and includes items relating to physical health, mental health, social and financial areas. Total scores range from 13 to 52 and higher scores indicate higher quality of life. This measure has accrued substantial evidence for reliability and validity (Thorgrimsen et al., 2003) and has been endorsed as the measure of choice for quality of life for use with people with dementia (Moniz-Cook et al., 2008).

The Cornell Scale for Depression in Dementia (CSDD, Alexopoulos, Abrams, Young, & Shamoian, 1988) is a measure of choice for patient mood in the UK and a 19-item scale that has demonstrated sensitivity to change in treatment studies (Alexopoulos et al., 1988; Moniz-Cook et al., 2008). The measure rates depression in five broad categories (mood-related signs, behavioural disturbance, physical signs, biological functions and ideational disturbance) using information from interviews with caregivers and participants. Scores above ten indicate a probable major depressive episode while scores above 18 indicate a definite major depressive episode. Missing items were replaced using the lowest possible score (zero).

The Goal Attainment Scale (GAS; Kiresuk & Sherman, 1968) Light Model (Turner-Stokes, 2009) was used to measure resident progress over the course of the intervention and to evaluate an intervention outcome of positive adjustment. GAS has been found to have sensitivity as an outcome measure (Gordon, Powell & Rockwood, 1999; Rockwood, Stolee, & Fox, 1993). An adapted version involving a single goal collaboratively agreed by resident, staff (and family where available) was applied. The importance, difficulty level and pre-existing achievement status of the resident's target goal were agreed at baseline. Please refer to Table 10 for scoring details.

The Index of Relocation Adjustment scale (IRA; Prager, 1986) was selected as an overall, general measure of adjustment and referred to the ability of older adults to cope with different demands and to stabilise as members of a residential home community (Lee, Woo, & Mackenizie, 2002). The scale (see Appendix F) is completed with the resident and has six-items. It uses a four-point Likert scale (0=completely disagree to 3=completely agree) and was adapted for this study to include pictures of faces ranging from very unhappy to very happy. The total score ranges from zero to 18 and higher scores indicate greater adjustment. The use of the IRA was explorative as the scale's psychometric properties have yet to be evaluated for use with people with dementia. Support for its reliability and construct validity have been accrued (Bekhet & Zauszniewski, 2014; Prager, 1986). Missing items were replaced using the mean score for up to two missing items, otherwise no score was recorded.

Family measures.

The Satisfaction with Care at the End of Life in Dementia Scale (SWC-EOLD, Volicer, Hurley, & Blasi, 2001) was selected to assess the families or carer proxies' level of satisfaction with the care given to their relative with dementia. The scale has ten items and uses a four-point Likert scale ranging from strongly disagree to strongly agree. The total score ranging from ten to 40 represents a summation of all ten items, with higher scores indicating more satisfaction. The measure has accrued empirical evidence for being reliable (Cronbach's α = 0.83) and valid as indicated by correlation coefficients ranging from 0.68 to 0.8 (Kiely et al., 2006).

Staff Measures.

The Sense of Competence in Dementia Care Staff (SCIDS, Schepers, Orrell, Shanahan, & Spector, 2012) measure was selected to assess self-perceived sense of competence in care staff. The scale involves 17 items covering four subscales (professionalism, building relationships, care challenges, and sustaining personhood) and uses a four-point Likert scale ranging from not at all to very much. An example item includes "How well do you feel you can offer choice to a person with dementia in everyday care (such as what to wear, or what to do)?" SCIDS has accrued evidence of acceptable to good internal consistency and moderate to substantial test–retest reliability (Schepers et al., 2012).

Timing of measures

The FAST was collected at baseline with staff or family to check that residents met the inclusion criteria. The QOL-AD and CSDD were completed with the resident and where this was not possible with the staff or family carer about the resident, at baseline, time two and time three. The IRA was completed at all three time points. GAS was collected with the resident and a staff or family carer at baseline and time two. The SWC-EOLD and the SCIDS were also collected at these times.

Qualitative data

The following were collated and formed the sources of qualitative data; transcripts of the semi structured interviews with staff who had led a SettleIN programme, SettleIN workbooks that contained field notes recorded by staff or families and field notes encompassing observations and feedback received during measure collection by the research team.

Analysis

Quantitative.

Descriptive statistics summarising the individual demographic and clinical characteristics of participating residents, carers and staff leads during the feasibility phase are reported. Linear mixed model analyses using Statistical Package for the Social Sciences (SPSS) version 21.0 (IBM, 2012) were completed to evaluate changes in scores over time on the QOL-AD, CSDD, and IRA at two time points and SWC-EOLD and SCIDS at one time-point. GAS score analysis evaluated progress made in residents' personal goals at one time-point.

Statistical Power. Due to a lack of methodologically equivalent prior research, a conservative effect size (f = 0.3) was used to conduct a power analysis for this study. Using G*Power 3 (Faul, Erdfeider, Lang, & Buchner, 2007) it was calculated that a minimum of 24 resident participants (with or without carer) would be required to achieve sufficient power (0.8) at a .05 level of statistical significance. However, a full analysis of the clinical effectiveness of SettleIN is outside the scope of this study due to the preliminary focus on intervention development and exploration of feasibility.

Qualitative: Thematic analysis.

The staff interview transcriptions, field notes in SettleIN workbooks and researcher field notes were made anonymous and imported into the specialist qualitative data and research management software, NVivo, version 11 (QSR International, 2015). NVivo was selected for being one of the research industry standard tools and appearing flexible, comprehensive and reasonably intuitive (Lewis, 2004).

All of the data was then systematically coded in accordance with the grounded theory guidelines described by Strauss and Corbin (1990). In line with hypotheses, a priori codes of feasibility, resident outcomes, and family satisfaction were created. All other codes were derived from the data analysis process after three rounds of open coding. Axial coding was completed to further structure, group and create categorised layers of the data into core themes. Selective coding was then applied to the more prominent and interesting themes during the in-depth analysis. These themes were then considered for relevancy and relationship to an a priori code. Constant comparison of each case and dataset was applied to ensure consistency of coding. Each new code was reviewed against previously analysed data sets to identify evidence of data that concurred or contrasted with any developing themes (Harry, Sturges, & Klingner, 2005).

Reliability and validity. The lead researcher held a critical realism philosophy where the actuality of SettleIN feasibility and utility was sought while the meanings individuals made of their experiences and the varied care home contexts were also recognised (Ponterotto, 2005). To minimise reflexivity and increase the credibility of findings two independent volunteers rated two randomly selected staff interviews and one researcher field note (Marques and McCall, 2005). Steps to validate results included inviting participating care home managers to appraise and check a summary of the qualitative findings (Potter, 1996).

Results

Phase II: Feasibility Study

Baseline characteristics.

The eight female and five male residents included in the study ranged in age from 70 to 97 years old. Eleven participants were from White-British backgrounds (85%). Demographic characteristics are presented in Table 6 below.

Of the 24 staff, two withdrew from the study after SettleIN training had been completed. The remaining 22 staff ranged in age from 18 to 64 years and 45% used English as a second or third language. Their experience in caring for people with dementia ranged from five months to 27 years and averaged nine years across the group. Demographic characteristics are presented in Table 7 below. Of the 22 trained staff, 15 were assigned to lead or co-lead delivery of SettleIN for a new resident while one was a deputy care home manager who intended to provide support to staff leads. The remaining six staff awaited assignments to a dyad following new resident recruitment.

Training.

A three-hour planned training session was often condensed to one and a half hours due to limited availability of staff.

Measure collection and attrition.

The flow of intervention measure collection and attrition is presented in Figure 1. In line with expectations, the majority of baseline demographic scores such as for age, nationality, ethnicity and severity of dementia were found to violate the statistical assumptions of normality. The high levels of missing data are presented in Table 8 and show that the majority of data was unable to be collected directly from the

Table 6

Demographic characteristics of resident participants

Characteristic	N (13)	%
Gender:		
Female	8	62
Male	5	38
Age:		
70-74	1	8
75-79	0	0
80-84	1	8
85-89	7	54
90-94	0	0
95+	4	31
Ethnic Group:		
White (British, Irish, other)	11	85
Asian (British, Indian, Pakistani, Bangladeshi)	2	15
Martial Status:		
Married	2	15
Single	1	8
Widow/Widower	8	62
Unknown	2	15
Dementia Diagnosis:		
Vascular	2	15
Alzheimer's	6	46
Unspecified dementia	5	38
FAST score:		
4	3	23
5	1	8
6a	0	0
6b	0	0
6c	2	15
6d	1	8
6e	6	46
Co-occurring Comorbidities:		
≤ 3 conditions	6	46
> 3 conditions	7	54

Note. Percentages are rounded so may not total to exactly 100%

Table 7

Demographic characteristics of staff participants

Characteristic	N (22)	%
Gender:		
Female	20	90
Male	2	9
Age:		
18-24	3	14
25-34	4	18
35-44	7	32
45-54	5	23
55-64	3	14
Job Title:		
Health Care Assistant	13	59
Activity Coordinator	2	9
Senior Health Care Assistant	5	23
Deputy / Team Leader	2	9
Years working with dementia:		
0-4	5	23
5-9	10	45
10-14	2	9
15-19	2	9
20-24	2	9
25-29	1	5

Note. Percentages are rounded so may not total to exactly 100%

residents. This was due to a resident's inability to complete questionnaires or unavailability due to illness (1), hospitalisation (n=5) or death (n=4) at the time of data collection. Overall, the IRA was well received by residents. Of the twelve attempts made to collect IRA at baseline, nine were acquired of which one had missing items.

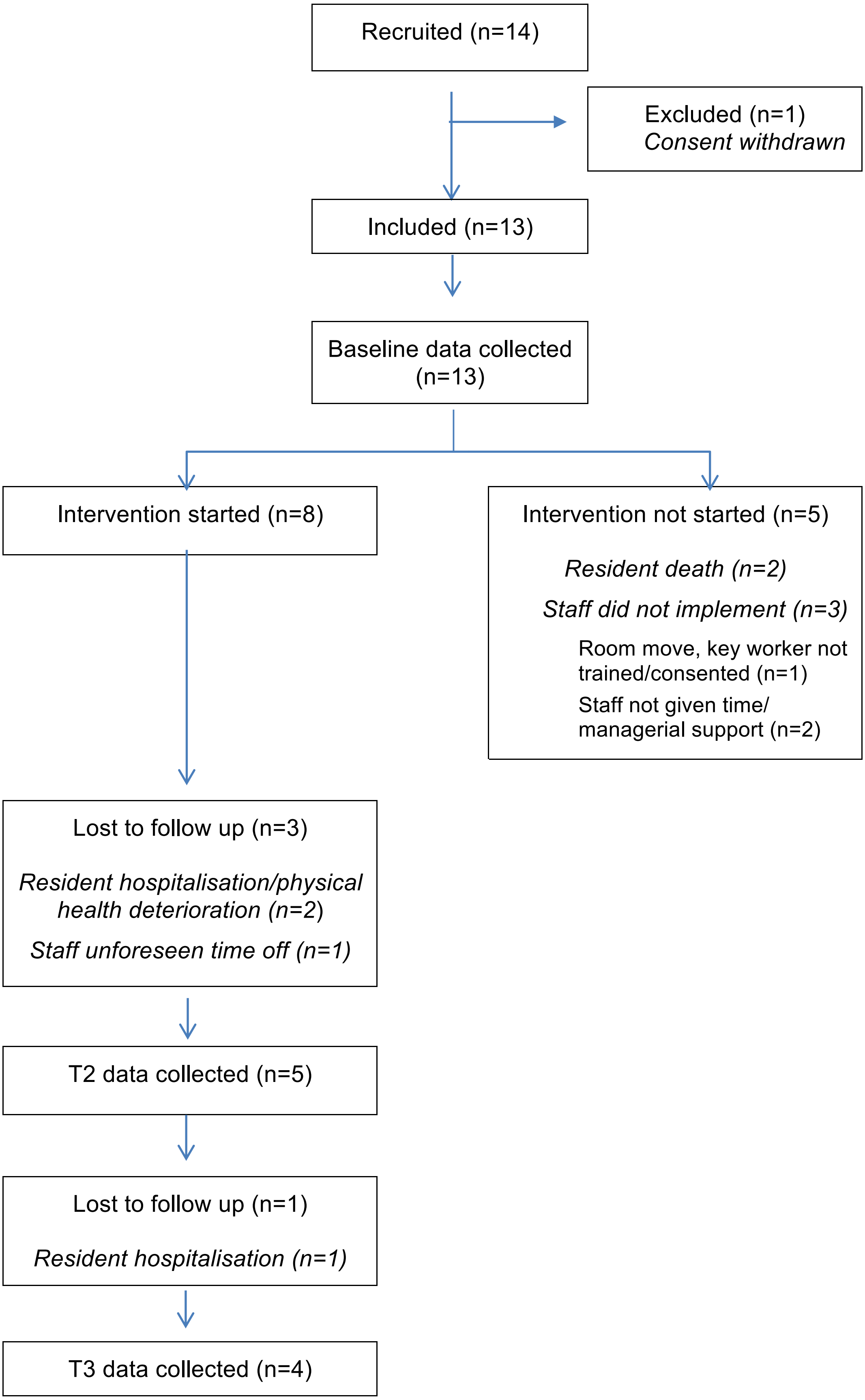


Figure 1. Flow of intervention measure collection and attrition

Table 8

Instances of missing measure scores by respondent and measure

Respondent	Measure	Baseline (N13)	Retained (N5)	Time 2 (N5)	Time 3 (N4)
Resident	QoL-AD	8	2	2	2
Resident	CSDD	12	4	2	1
Resident	IRA	4	0	1	0
Staff	QoL-AD (Resident)	2	0	0	2
Staff	CSDD (Resident)	2	0	0	1
Staff	SCIDS*	0	0	1	n/a
Family	QoL-AD (Resident)	2	1	0	1
Family	CSDD (Resident)	8	5	4	4
Family	SWC-EOLD	5	2	0	n/a
Total		43	14	10	11

Note. *N=15 (more than one staff member delivered SettleIN for two participants)

SettleIN intervention outcomes for residents.

The mixed model analyses using all available baseline (n=13), time two (n=5) and time three (n=4) data indicated that the missing data was too substantial to enable any conclusions to be drawn regarding the influence of SettleIN over time on resident quality of life, mood and adjustment. For descriptive purposes Table 9 displays the means, standard deviation and mean change for the retained participants at post intervention (n=5) and follow-up (n=4).

The goal attainment analyses were similarly constrained to low numbers of participants. Of the five participants who were able to agree a goal at baseline, one was hospitalised so collection of time two data did not take place. For one reluctant resident their goal of going out of the care home was unlikely to be an indicator of healthy adjustment. For the remaining three residents, results are presented in Table 10 for descriptive purposes. Two participants achieved a better than expected outcome for their individual goal (with +1 and +2 scores respectively) while one attained a worse than expected outcome (-1).

Table 9

Means, standard deviation and mean change from baseline

Measure	Time point	N	Mean (SD)	Mean Change
QoL-AD	Baseline	5	30.4 (4.8)	
	Post	5	34.1 (3.5)	+3.7
	Follow-up [a]	2	31.8 (1.1)	+1.4
CSDD	Baseline	5	4.4 (2.8)	
	Post	5	5.0 (4.4)	+0.6
	Follow-up [a]	3	1.7 (1.5)	-2.7 [b]
IRA	Baseline	5	8.2 (2.4)	
	Post	4	8.9 (2.2)	+0.7
	Follow-up	4	7.3 (4.0)	-0.9
SCIDS [c]	Baseline	5	60.8 (4.7)	
	Post	5	66.8 (1.8)	+6.0
SWC-EOLD [c]	Baseline	3	25.7 (4.5)	
	Post	5	27.4 (4.7)	+1.7

Note. QoL-AD= The Quality of Life in Alzheimer's Disease, CSDD=The Cornell Scale for Depression in Dementia, IRA=The Index of Relocation Adjustment scale, SCIDS=The Sense of Competence in Dementia Care Staff, SWC-EOLD= The Satisfaction with Care at the End of Life in Dementia.

[a] Too many missing intra-scale scores prevented overall scores from being included for some of the four participants.

[b] A negative mean change indicates a decrease in negative mood symptoms.

[c] All measures and N pertain to resident participants with the exception of SCIDS which relates to staff who led SettleIN for the residents and SWC-EOLD which relates to family.

Table 10

Results of goal attainment for the three residents who were able to agree a goal.

R	Importance	Difficulty	Baseline		Achieved				Total
1	Medium	High	Some function	√	Yes	√	A lot more	√	+2
							A little More		
							As expected		
			No function		No		Partially achieved		
							No change		
							Got Worse		
2	Medium	Medium	Some function		Yes	√	A lot more		
							A little More	√	+1
							As expected		
			No function	√	No		Partially achieved		
							No change		
							Got Worse		
3	High	High	Some function	√	Yes		A lot more		
							A little More		
							As expected		
			No function		No	√	Partially achieved		
							No change	√	-1
							Got Worse		

Note. R= Resident, Importance= Importance of goal to the patient and Difficulty= Difficulty of goal as perceived by researcher both with response options of low, medium, high. For the scoring; If the resident achieved the expected level, a score of zero was awarded. If residents achieved a better than expected outcome these were scored as either +1 (a little better) or +2 (much better). If residents achieved a worse than expected outcome -1 (somewhat worse) or -2 (much worse) scores were awarded. Goal descriptions have not been included as they may reduce participant anonymity.

SettleIN intervention outcomes for staff and family.

The mixed model analyses using all available SCIDS and SWC-EOLD data also indicated that the missing data was too substantial to enable any firm conclusions to be drawn regarding the influence of completing SettleIN on i) staff sense of competence and ii) family satisfaction with care. For descriptive purposes Table 9 shows the mean change scores for the scales pertaining to these outcomes and the residents retained at follow-up.

Qualitative Results

Six post intervention staff interviews, four sets of SettleIN workbook field notes, and 11 researcher field reports informed the qualitative results below. Themes categorised by relevance to hypotheses and detailed in Appendix G indicated that SettleIN was *better than care-as-usual*, *easily integrated into care with some though not all residents,* was *beneficial to staff* and *linked with both positive change* and *no benefit* for resident quality of life and mood. Different *care home and staff conditions* and differences in the *level of family involvement* were barriers to programme implementation and module completion. Additional themes about potential enhancements to SettleIN derived from the data included *minor changes*, *further simplification* of the programme and *reduced dependency on family*.

Independent rating identified a small number of instances where data had not been coded or only one code had been applied where two codes may be relevant. No additional codes were proposed and subsequent checks for consistency did not change axial codes or overall themes.

Hypotheses

1. **SettleIN will be feasible for care home staff to implement and deliver.**

SettleIN is easily incorporated into care and better than care-as-usual.

Staff who led and supported the programme delivery found SettleIN to be easy to understand and use. When asked explicitly about the language employed within the SettleIN workbook they confirmed that overall the language was clear and the programme well explained.

> *'…It's quite self-explanatory really… once you have got that module in front of you then it's got it all there, what you have to do… Completely feasible.*' (Health Care Assistant (HCA): Interview 1)

In the interviews, staff spoke of the overall programme duration being practical and four staff found the proposed length of time for each activity noted in the SettleIN workbook either helpful or accurate. SettleIN was incorporated into normal care activities by staff who delivered the programme.

> *'I'd do it throughout the whole day…[activities] were average between 10 and 20 minutes. I thought [the programme length] was really good actually…then when I done my care plans at night time then I would write it in, because I was doing my books anyway…'* (HCA: Interview 2)

> *'…it was only short sections... so it was little and often so that was quite good.'* (Senior Health Care Assistant (SHCA): Interview 4)

Staff concurred with those consulted in the development of the programme when they deemed the SettleIN content to be appropriate and acceptable. Minor amendments to three terms and a record sheet within the workbook were suggested.

> *'You get to spend some time with a resident, ask them questions you wouldn't normally ask… it would be quite a good part of... if we got a new resident…I think it's a good programme.'* (HCA: Interview 5)

The interviews indicated mixed responses from staff as to whether SettleIN was different from or similar to care-as-usual. One interviewee suggested it was both and explained that the one to one interaction with the resident was similar while the content of the interaction was different. Four staff indicated that the SettleIN was better than care-as-usual for a number of different reasons. These included; the piece of mind and continuity of life SettleIN enabled for residents, the insight facilitated for staff into a resident's pre-placement life and, aid with getting to know a new resident rapidly.

> *'I would say it's quite similar [to care-as-usual] …because we would have found out what everybody found out from him, we would have found it out eventually. It's just made it a lot quicker.'* (SHCA: Interview 4)

> *'I gained his trust…so I found out quite a lot about him, which then I will pass onto other members of staff… [SettleIN] does help … instead of everybody just trying to be 'Hello. What's your name? What do you like to do?' You've actually got somebody that can actually talk with [the resident] properly and actually go into detail with them.'* (HCA: Interview 2)

SettleIN is enjoyable and beneficial for staff. The staff who delivered a SettleIN programme stated that they enjoyed or liked using the programme.

Interview responses emphasised an array of benefits to staff including; a sense of achievement, increased confidence, learning and development, knowledge sharing between staff and development of bonds with residents. One staff member suggested all staff should do SettleIN as it develops staff understanding of adjustment.

> *'We achieved something... it was like I achieved something with him, that I might have got through to him, like just knew a little bit more about him.'*
> (HCA: Interview 5)

> *'I think [staff] should do it…because it gives them a better understanding of all aspects of that for [residents] settling in*.' (HCA: Interview 1)

SettleIN may not be suitable for all residents. Three staff spoke of the difficulties they experienced when attempting to deliver SettleIN with two residents. Staff explained that one resident's minimal communication style meant it was hard to engage with the resident and determine if there was any enjoyment of the SettleIN activity. In a separate instance, staff explained that a new and reluctant resident who insisted she could live independently was unreceptive to and suspicious of SettleIN activities. Staff concluded that SettleIN may not be suitable for all residents despite it's utility.

> *'I think it depends solely on the resident…if they are not engaged and they don't want to, it is very difficult for you to actually do the SettleIN. With this resident they weren't engaging, they weren't really talking, their emotions were hidden, so it is very challenging. So in that respect I wouldn't actually have used the SettleIN for that resident. But other residents maybe.'*
> (SHCA: Interview 4)

> *'... it's a shame we couldn't have done this programme with [Resident's name], one of our other people... it's a very useful thing with some of the residents…I don't think [SettleIN is] inappropriate at all, but you've obviously got to make a sort of decision…to whether or not that person is suitable for it.'* (SHCA: Interview 3)

SettleIN is hard to implement and deliver in some care home and family conditions. Staff described two main barriers to implementation and delivery. While some care home staff easily integrated SettleIN into care-as-usual, staff in two care homes described no and partial programme implementation due to lack of time, high workload, and low staff to resident ratios.

> *'I don't have that much time to deal with these things… Taking time... I cannot.'* (HCA: Interview 6)

> *'Care staff…mentioned their high workload…there were only four [staff] to care for many residents (32)…[staff] suggested that more care workers to spread the work load more may help…[and] both reiterated that it was a lack of time that prevented them from completing the SettleIN modules. Both key workers still expressed interest in the programme and thought it was worthwhile.'* (Researcher 4)

Difficulty in contacting families and minimal family involvement were factors that prevented full delivery of SettleIN and optimal outcomes being realised. While not all families were unsupportive, staff described how they were unable to complete some aspects of the SettleIN modules as they were waiting on family provision of information and items for activities which in some cases never materialised or arrived late into the programme duration.

> *'…yet they weren't so helpful when I tried explaining … I need the pictures… because this finishes in two weeks…[The family said] we will bring it next week, came next week, nothing…[and regarding another item they said] Oh well [he] won't look at a calendar anyway.'* (HCA: Interview 2)

In summary, the evidence does not support the first hypothesis that SettleIN, in its current form, was feasible for staff to implement and deliver. While staff reported SettleIN had overall sound design, clarity and was easy to use within normal care activities they offset these points with advice that delivery was more difficult with some residents over others and some activities were dependent on family input that did not always materialise. Overall, there were many occasions where implementation was not started or delivery was hampered and time stretched staff in some care homes did not attempt SettleIN.

2. **People with dementia will experience and retain an improved mood and higher quality of life after having completed SettleIN.**

Positive changes observed though not always recognised. Staff reported at least one positive change for the residents who received SettleIN including the aforementioned reluctant resident. The programme also appeared to help facilitate person centred care and reinforce with staff that people with dementia can learn new information and new skills.

> *'SettleIN…helped a lot because... I know that now he's a late riser…So instead of going up there first thing in the morning, I'd got up there like half*

> *nine...I was trying to like blend both present and …support him [to] go back to how he was…before he came here… In the end you'd go in there and he'd already be up sitting in the chair waiting, so he got into a routine of it again.'* (HCA: Interview 2)

Staff observed residents' increased familiarity with people and their new surroundings.

> *'…. about four or five days into [SettleIN] he actually remembered my name.... after three days as well that I hadn't been here…and I asked him and he said it straightaway! There was clapping… I think it's good how …it actually made him settle in…it was like a challenge for him…when I used to say…'Can you show me to the lounge?'. At first it was like going for a long mission, around the whole home…in the end that got really easy...because he knew his way*.' (HCA: Interview 2)

> *'I said to her, 'Can you remember where you are now, because obviously we've moved your room', she said, 'I am number [X], and it's literally just down the corridor'…It was quite good…it's nice that she knows where she is.'* (SHCA: Interview 3)

Family and staff reported improvements in resident mood and resident's increased trust and development of connections with others in the care home.

> *'Her mood has improved, is good. She recognises me.'* (Family carer noted by Researcher 1)

> *'He started engaging in a conversation with another resident, on his own.'* (SHCA: Interview 4)

Staff observed a reduction in unwanted resident behaviour and an increase in engagement with care home life and opportunities.

> *'...she talked a lot more about certain things. If you start off on something she will get more involved in it.'* (HCA: Interview 1)

> *'…when he first came here he was quite aggressive with other residents …two or three times a day…I haven't seen him lash out properly in ages.'* (HCA: Interview 2)

and about the same resident,

> *'He's spending more time with others…more involved in group discussion…definitely came out of himself more. He was asking to go home a lot more than he does now.'* (Deputy Manager noted by Researcher 5)

No benefit for residents. In contrast, three of the same staff perceived that the identical residents had not benefited from the programme. One instance appeared to refer to the overall impact of the programme while the other instance related to the difficulty staff found in communicating with a resident and discerning differences in his responses.

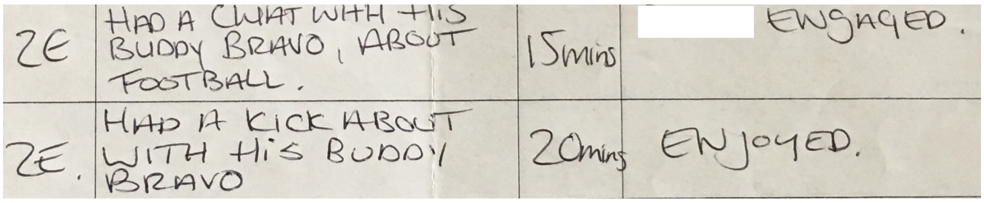
> *'I think with her it just didn't work.'* (SHCA: Interview 3)

> *'I don't think this resident benefited from it, to be honest*. (SHCA: Interview 4) and about the same resident, *I wish I could answer these questions...he*

doesn't change…To tell you the truth I can't tell you what mood he is in…he's just a blank... but he's joining in.' (HCA: Interview 5)

Resident reports varied widely. Variance in mood was highlighted directly by new residents. After completing SettleIN, one resident stated '*they seem very nice here'* while another resident explained '*she just loves it* [in the care home]' and enjoys meeting people with '*different nationalities'.* Alternatively, another resident disclosed that she thought '*I have no future, life has turned on me, I'm only restless because I don't want to be here.'*

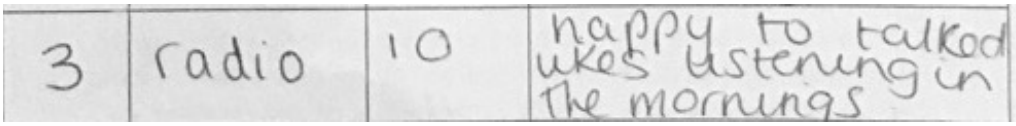
At the start of SettleIN a new resident shared a difficulty he was experiencing with his mood and explained '*I wake a lot in the night because I'm not as active as I would normally be.'* After SettleIN had been running for three weeks, a field note showed that the same resident's interest in football had been identified by staff and a connection facilitated with a staff buddy. The resident appeared to enjoy the football played with the buddy when it was subsequently arranged for him.



2E	HAD A CHAT WITH HIS BUDDY BRAVO, ABOUT FOOTBALL.	15mins	[redacted] ENGAGED.
2E.	HAD A KICK ABOUT WITH HIS BUDDY BRAVO	20mins	ENJOYED.

(Field Note 1: recorded by SHCA)

Another field note highlighted a resident's engagement with an activity from the Lifestyle module. The note indicates the resident's mood and staff identification of the resident's preferences regarding a morning routine.



3	radio	10	happy to talked likes listening in the mornings

(Field Note 2: recorded by HCA)

In summary, the second hypothesis was not upheld as resident outcome results were mixed and limited by the small number of participants who received the intervention. The issue of sustained results was not investigated through qualitative methods.

3. **Family carers will experience higher satisfaction with care after their relative has completed SettleIN.**

There was little qualitative data involving the resident participants' families from which to draw a theme regarding family satisfaction with SettleIN. Though scarce, family reports were positive. In summary, no conclusion could be drawn regarding the third hypothesis.

> *'She's improving – not mentally or physically but she's more used to being there, she's really happy so far.'* (Family carer noted by Researcher 1)

Improvements to SettleIN.

Staff proposed that SettleIN might be improved by; simplifying the core offering, reducing the frequency of repetition and intensity of some of the questions, and by making minor amendments to the activity schedule, terminology and recording sheets. The difficulties reported in working with some families also highlighted the need to reduce or remove dependency on family for completion of module activities.

> *'The layout of the recording sheets… there wasn't much space to actually write what you'd actually done and what he done… [The planner] should just be a block for however many units…[activities] should be completed in that week, instead of the days.'* (HCA: Interview 2)

Validation of Qualitative Results.

Two of the five care home managers responded to the invitation to review the qualitative findings. They confirmed that the findings appeared to be representative of their experience. No counter theme examples were identified.

Discussion

Summary of findings

This study provided valuable insights into the acceptability and feasibility of implementing SettleIN, a healthy adjustment programme led by care home staff for new residents with dementia. In a consultation phase, experts by profession and by family carer experience responded positively to the structure, content and clarity of the programme and accompanying documentation. During a feasibility study, in care homes where SettleIN was implemented, staff found SettleIN to be easily integrated into care, better than care-as-usual, and of benefit to staff. Staff and family reported observations of positive quality of life and mood outcomes for residents were unsubstantiated by validated assessment measures and inconclusive mixed model analysis, that were also exacerbated by a high attrition rate. Care home uptake was very low and intervention feasibility concerns related to staff time, family involvement and suitability of the programme for all new residents. The captured concerns and ideas for improvement provided the lead researcher with an understanding of likely reasons for non-implementation and incomplete delivery.

Feasibility of Implementing and Delivering SettleIN

Implementation.

This data centred around contrasting reports of ease and lack of time. Care homes with higher overall CQC ratings, who appeared to have consistent managerial support for the programme and stable, well balanced staff-to-resident ratios described having no difficulty in implementing SettleIN. Alternatively, some of the care homes where staff described being very stretched or task focussed and where managers appeared to have little time to support staff undertaking the research, struggled to begin implementation. These types of challenges are not uncommon in care home research and emphasise why interventions need to be 'light touch' and easily incorporated into usual care practice (Lawrence et al., 2012; Luff, Ferreira, & Meyer, 2011).

SettleIN was not started on four occasions across three participating care homes. While the staff reports of being too time-short and busy were somewhat expected (Maas, Kelley, Park, & Specht, 2002) implementation was ceased for two further and separate circumstances; unforeseen leave for a trained staff participant, and allocation of a non-participating staff member following a recruited resident's change in rooms. These unanticipated scenarios would ideally be mitigated in a subsequent trial through improved planning and upfront discussion with managers about continuity of implementation.

Delivery.

The data collected from staff about the feasibility of SettleIN focussed on variance in programme suitability for residents and dependence on family involvement. Several studies have demonstrated that family involvement is linked with positive outcomes for residents (Castro-Monteiro et al., 2016; Maas et al., 2004). However, in this study, when families did not engage with staff to provide requested items or information, staff were unable to fully deliver SettleIN. Redesigning SettleIN activities to be non-family dependent would mitigate this barrier to delivery.

Staff reported that SettleIN may not be suitable for all new residents and cited challenges using SettleIN with residents who they found difficult to communicate with or difficult to engage with due to their total and persistent rejection of relocation. Ideas for overcoming these challenges were not volunteered by staff during post intervention interviews. All new residents are entitled to support with adjustment therefore further investigation of how to overcome and adapt SettleIN to address these specific scenarios is needed.

Sustained Improvements in Resident Quality of Life and Mood

Although clinical effectiveness of SettleIN was not the main objective of this study, results for resident outcomes including that of no perceived benefit, were consistent with findings from a recent systematic review (Cabrera et al., 2015). The authors concluded that while there was some evidence for the potential of psychosocial interventions to improve resident quality of life, overall there was not enough evidence to support the effectiveness of non-pharmacological interventions in care homes.

In comparison, and with caution due to possible bias, the hint that some residents may have experienced a positive change in quality of life following SettleIN was consistent with other reviews that have found psychosocial interventions improved quality of life and mood (Lawrence et al., 2012; Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Moyle, 2010). Non-specific factors, such as care home culture or natural adjustment may have contributed to the positive changes that were observed and can not be discounted (Hoe et al., 2009; Maas et al., 2002). Also of note, is that this study's mixed results did not fit with an experienced care home manager's expectation.

> *'There was no difficulty in implementing the programme at all…I think that family carers would experience higher levels of satisfaction with care after SettleIN. Our experience was limited to the one resident and I do not think the [no observed change] outcome was what I would expect if the*

programme had been carried out with more significant numbers.' (Care Home Manager, during informant feedback)

Staff Sense of Competence and Family Satisfaction with Care

Suggestion of advantages to family and staff from using SettleIN was aligned to other studies that have found benefits of psychosocial interventions. Lawrence et al. (2012) review described interventions that helped staff to "see beyond the illness" and develop a mutual understanding and respect between staff and families. An additional and potentially specific study is required to investigate the third hypothesis with careful consideration taken over how to gain meaningful and optimal data from families.

Improving SettleIN

SettleIN would be enhanced by simplifying the core offering. This could be achieved by condensing or removing the needs assessment and future planning components to allow for concentration on the main section, promoting healthy adjustment. Reducing the number of activities within each module and reducing the frequency in which the activities are undertaken may also simplify SettleIN and make implementation more feasible. Removing any dependency on family contribution to activities would aid intervention delivery without preventing families from being involved if they wished to do so.

A review of the question prompts provided and how they are utilised would ensure they are not experienced as intense. Furthermore, healthy adjustment aspects of residents feeling safe, comfortable and a sense of control may be better targeted by designing an activity involving a specific Rogerian core condition approach and active listening based support (Rogers, 1957). The overall length of the programme could be reviewed. Amendments made to the activity schedule to display weekly rather than daily units would be better aligned to staff shift work.

Minor alterations to terminology such as replacing ‘buddy’ with ‘friend’ and providing more space within recording sheets would also address staff feedback.

Methodology Strengths and Limitations

Consultation with over forty-five relevant experts including family representatives, was a strength of the intervention development and led to a high level of confidence in SettleIN prior to trial. However, this study met with many of the attrition related obstacles that are common to conducting research with people with dementia in care home settings including participant death and hospitalisation, low staffing levels and inconsistent managerial support (Luff et al., 2011). The high attrition rate suggests the positive outcomes for residents following SettleIN may be from a biased sample and other residents may have had less benefit.

While the study was underpowered, it has provided valuable insight into the target sample size required for a pilot of SettleIN. If an assumed retention rate of 30% (similar to this study) was applied, over 80 participants would be required to ensure a sample of 24 were retained and to met the statistical power calculation requirement. The addition of a control group would add strength to this study’s design though the increase in target sample size required including expected control group attrition would also need to be considered (Robson, 2002).

The use of researchers other than the lead researcher for data collection at post and follow-up time points aimed to minimise bias in participant response. However, inconsistent measure administration (despite all researchers receiving the same training and supporting documentation) may have contributed to other bias and missing data. Using mean scores for missing data within some of the scales may also have led to bias. Although, the application of a mixed model analysis that accounted for missing scores across measures also prevented overly optimistic interpretations being made (Barr, Levy, Scheepers, & Tily, 2013).

An advantage of utilising a mixed method design was that it enabled the identification of positive resident outcomes and staff benefits resulting from the use of SettleIN that would otherwise have gone undetected. Triangulation, inter-rater reliability tests, negative case inclusion, and member check processes all ensured that the themes derived from qualitative data had credibility and were representative of participant experience (Creswell, Klassen, Plano-Clark, & Smith, 2011).

Clinical implications.

This study confirms how difficult some care homes find implementing new interventions, even those they perceive as worthwhile. Currently there is no best practice guideline for care homes about how to provide assistance with healthy adjustment to a person with dementia in their first few weeks of care home residency. SettleIN provides a first step towards development of best practice in response to the growing numbers of people with dementia who are likely to reside in care homes over upcoming years.

Research implications.

A well powered pilot of an enhanced version of SettleIN is needed to establish if it is feasible to implement across a wide range of care home settings and if residents experience improved quality of life and mood following SettleIN delivery. For wide care home adoption of SettleIN to take place, staff in settings with low staff to resident ratios would need to consider the current barrier of not having time to implement as surmountable. Improved partnership and training may be one way of achieving this.

The current study was ambitious in its use of a mixed method design and attempted to capture resident, staff and family outcomes. A future study may be better to focus on gathering full sets of quantitative data for consideration alongside the qualitative results from this study. Alternatively, a mixed method design could be retained and a focus limited to resident outcomes only. As proposed earlier a separate study for investigating family and staff outcomes would be desirable. These options rather than a repeat of the current design may help ensure a complete data set is acquired.

While broad inclusion criteria can aid trial recruitment it may be worth lowering the level of FAST score criterion to decrease the likelihood of a resident hospitalisation or death impacting a future pilot though this can never be fully mitigated. It may also be advantageous to ultimately investigate the ‘bare minimum’ of the SettleIN programme required to produce positive effects for residents and staff.

Conclusion

In summary, despite its limitations, this is the first known study of an intervention to support healthy adjustment in people with dementia in the early period of residency following placement in a care home. A number of core feasibility concerns and a high attrition rate mean intervention improvements are required. A second pilot is needed to investigate the impact of an enhanced SettleIN on new resident mood and quality of life.

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Part III: Critical Appraisal

Introduction

This appraisal provides a critical reflection on Part 1 and Part 2 of Volume 1 of the clinical psychology doctoral thesis. It begins with a commentary on conducting a literature review and highlights some of the topic selection, study appraisal and data synthesis challenges encountered. The appraisal of the empirical paper details reflections on the choices made during the feasibility study design, intervention development and study implementation. Challenges experienced while working with the care homes and research volunteers are considered. Possible directions for future research are offered along with proposals for how the major research project might be approached differently, based on the experience of conducting this study.

Literature Review

Difficulty in determining the topic

An original idea agreed with my supervisor to update a literature review about adjustment following the placement of a person with dementia in a care home, did not come to fruition as planned. Initial searches yielded plenty of potential papers. However, a structured search indicated that there were too few papers available for a meaningful review. This was a discovery late into the overall research project timeline due to prioritisation of empirical study consultation and recruitment phases. Similarly, preliminary searches of an array of alternative topics relating to adjustment had either already been published or yielded a low number of papers. I was struck by the absence of papers that focussed on care home process, strategies or interventions for promoting healthy adjustment to long term care for new residents. With the increasing government and media focus on dementia I had expected there to be best practice guides within the literature. One paper published in June 2016 (Burke, Stein-Parbury, Luscombe, & Chenoweth, 2016) may inspire others to consider research in this domain.

It was with disappointment that I abandoned the idea of an adjustment focussed topic and searched for a different option. I discovered a literature synthesis on family involvement (FI) with care homes that had not been updated for some years. However, I was somewhat daunted by the large number of sub-topics it covered and how I might do justice to updating such a seminal paper. When the related search returned enough papers I decided to proceed. One bonus from arriving at a topic later meant I did not have to rerun the searches to update them and instead could focus on monitoring alerts for any new related publications.

Bias

The Cochrane Handbook for systematic reviews advises that it is well established that publication bias and selective outcome reporting are likely to have influenced which papers were available for selection and which data was available within each paper (Higgins & Green, 2008). Furthermore, selection bias may have influenced which papers the author included in this review, compounding systematic bias. To ensure the judgement of which papers are included are reproducible and to minimise bias it is recommended that an independent, non-content expert (blind to information about the article such as journal and authors) repeat the paper selection process. This would reduce the likelihood of a relevant paper being eliminated (Higgins & Green, 2008).

Critical appraisal of others' work

Upon reviewing the tools available for appraising studies I chose the Mixed Methods Appraisal Tool (MMAT, Pluye et al., 2011) thinking that it was both appropriate and may save time; I would only need to get to know one tool rather than learn about and then apply different tools to different study designs. In a number of ways, the opposite happened. While the MMAT was easy to use, it did not involve a numeric score that allowed for ranking of studies or, facilitate the capture of sufficient detail of studies' strengths and weaknesses. I considered this to be especially important as I felt acutely aware that I was evaluating others' hard work. Just as I would hope for any critique of my own work, any appraisal had to be as fair and as accurate as possible. Consequently, instead of saving time, I completed the critical appraisal twice; also applying the Kmet, Lee and Cook (2004) appraisal tools to all of the studies. I then compared my evaluations, increased my confidence in the outcome and gained detailed information to draw on for reporting the results. On reflection, it is likely that I would have saved time by using the Kmet et al. (2004) tools from the outset.

Synthesising large amounts of information

I found the reliance on text based descriptions in the seminal review about family involvement (Gaugler, 2005), unhelpful for being able to quickly and easily determine the key points being made for each topic. I quickly discovered that creating tables to simply and clearly represent a lot of diverse and multidimensional information can be difficult to achieve in a concise manner. In this case, caregiver burden and some types of involvement (such as the type 'report abuse') were not displayed as they were not in the papers included in the review. My initial hope and plan to provide a set of tables that comprehensively reflected all available evidence and distinguished the last ten years of developments across all four sub topics of FI (types, influences, interventions and outcomes) was set aside.

On reflection, I am satisfied with the end product and have learnt a lot about how to appraise studies, synthesise and present a wealth of information. I also hope the review has provided a useful update for dementia literature having highlighted the last decade of developments in FI with care homes, specifically following placement of a relative with dementia.

Empirical Study

Background Interest in Dementia

I knew before starting the DClinPsy that I wanted to conduct my doctoral research within the field of dementia. I had become increasingly interested in this area after deciding to change career and focus on work that felt meaningful to me. Family experiences, getting older and reading relevant articles in the British Psychological Society's Psychology magazine also added to my interest. My enjoyment of working with older adults during a clinical placement cemented the appeal.

Ethics

I was relieved and pleased with how quickly and easily ethics approval was acquired, especially when the study involved participants considered to be vulnerable. From submission to the UCL Joint Research Office to receipt of Research Ethics Committee approval took five weeks and was achieved by May 2015. While in reality it was not a short process and a lot of preparation work had been completed over the previous six months, this felt worthy of celebration. It meant the project could start in earnest and many of the challenges relayed by previous students about only getting approval very near to the thesis due date or never getting it at all, had been avoided.

Reflections on study design and methodology

After appraising my own study with the tools used in the literature review, albeit with the presumption of bias, the obvious weaknesses were the small sample size, lack of; randomisation, blinding and a control group as well as the very high attrition rate. However, strengths in reporting, use of appropriate measures, consideration of researcher influence and attempts to establish credibility through triangulation, inter-rater agreement and informant feedback were identified and appropriate for a feasibility study.

Mixed method approach and scope.

The use of a mixed method approach as recommended by the Medical Research Council guidelines for designing and evaluating complex interventions (Moore et al., 2014) was a strength of the study. It proved to be very helpful in understanding the SettleIN intervention application, difficulties and successes. However, there were many occasions throughout the project when I felt that one person could not develop and deliver a completely new intervention to research best practice standard in the time allotted. A sentiment foreseen by my supervisors and the reviewer of my thesis proposal who warned of the boldness of the project. Professor Ballard identified that there were 72 available work days over and above the other DClinPsy commitments in which to realistically complete the data collection for the study. At that stage optimism prevailed as the deadline was over a year away and I trusted my project management skills.

Ironically perhaps, despite all of the discussions that took place about the overly-ambitious nature of the project, scope continued to creep throughout the early period of design. More measures than originally intended were included to ensure consideration of feasibility and outcomes for multiple parties. These included a family satisfaction with care measure, a staff sense of competence measure and a resident goal attainment scale. I found myself attached to retaining the Index of Relocation Adjustment (IRA, Prager, 1986) as it was the only scale that directly measured resident adjustment following placement into care. While qualitative elements were included to meet design best practice they were also added to ensure output from the study in the event that recruitment was difficult.

In hindsight, an initial focus on resident outcomes would have been sufficient and an argument for this could have been made. I believe the inclusion of the IRA was a good idea as residents found it to be the easiest measure to complete of the three resident measures. It also gave a direct voice to the residents' perception of their own adjustment. I hope this study has paved the way for further application of the IRA with people with dementia and laid the ground work for a psychometric study. I believe the mixed method design did warrant an additional trainee to give optimum consideration to the design of the semi structured interview, conditions in which the qualitative data would be collected, and the thematic analysis. Further thoughts about the qualitative design are proposed in the analysis section below.

Intervention development and consultation.

Overall the intervention development and consultation phase of the project may be the strongest element of the empirical project. Developing the SettleIN intervention directly from theory and with time taken to think about the four key values I wished the intervention to espouse, helped with comprising the structure and content of the intervention. I sought to create an appealing, picture filled and professional manual with content of substance. I believe this was achieved.

Additional materials were developed including a flyer for distribution at a care home network event, a one-page overview for care home managers and a PowerPoint presentation used in the consultation session with the memory service team, which later formed part of the training pack. The choice to create attractive documentation so that it would stand out amongst other paperwork appeared to be the right one. The additional expense involved in printing materials in colour meant the original project budget was exceeded. I recommend that researchers consider this type of decision early on in their projects so that budgets and logistics are optimised.

Many aspects of the intervention were considered within each consultation. More effective planning of the group consultation sessions would have elicited in-depth data about anticipated impediments to feasibility. A slightly longer session with a focus on a subset of consultation topics and a fellow researcher to assist with the capture of all points being made were needed.

My external supervisor had suggested that consulting with 40 stakeholders was a sound target in usual intervention development practice. I was pleased to have surpassed this number by the end of the consultation phase and to have gathered the views of 47 diverse people with highly relevant experience. I was disappointed that my attempts to consult directly with people with dementia, facilitated by another consultee, did not come to fruition. Placement in a care home is a sensitive topic for many people and recruitment of people with mild to moderate dementia, who are likely to experience care home placement at sometime in their future, was expected to be difficult.

This phase of the project distinctly sparked my interest in creating feasible interventions. I have thought of additional ideas about how to improve SettleIN or create related interventions that address resident, staff and family unmet needs; that both fit with and go beyond ideas gathered during the study. I hope that I am able to work on these at some stage in the future.

Recruitment.

Recruitment within the short time frame in which a potential resident participant moved from meeting the inclusion criteria to having to be excluded was the greatest challenge. Each new resident needed to be identified, their family contacted by care home managers, lead researcher contact made and consent acquired, staff trained and the intervention started, all before the potential participant's residency had exceed four weeks.

This proved to be logistically difficult and often required researcher presence in two places. New residents from the five different care homes were sometimes identified in the same week by care home managers and staff availability for training often coincided with trainee placement days or weekends. Managing this challenge and being as flexible as possible to accommodate staff and residents was essential to project success. I was very grateful to clinical supervisors who afforded me the flexibility to juggle placement and project commitments.

Discussions about amending the inclusion criteria to enable residents' pre-intervention residency to be up to six weeks rather than four weeks took place with supervisors. In the end, this amendment was not applied before the decision to stop recruitment altogether was made. An extension to six weeks may have made recruitment easier. Though, the potential for confounding of study outcomes with naturally occurring adjustment would have been exacerbated and the lack of control group and variables would have made this difficult to account for (Robson, 2002).

One final point about recruitment is that I felt conflicted about the order in which consent was gained from the residents involved. In line with ethical protocol and care home manager requirements, I was unable to speak with residents until after I had gained consent from families to do so and gained consent for their relative to be involved. Therefore, where I was unable to speak to families and residents together, consent for the resident to be involved was granted by the family first as their designated proxy. The consent was then accompanied by an expectation that their relative would receive the intervention and be supported with adjustment.

Resident consent was gained directly (where capacity allowed) yet I felt awkward that there was potential for a situation to arise where a resident might express that they didn't want the intervention and the family could insist it was in a resident's best interests to receive it. I was grateful that this scenario did not arise yet remained worried about whether the intervention was being completed *with* the resident as opposed to being *done to* the resident. I noticed feeling simultaneously relieved and disappointed when a resident exercised their right to stop engaging with the intervention.

Measures and volunteers.

Baseline scores for one measure, The Sense of Competence in Dementia Care Staff (SCIDS, Schepers, Orrell, Shanahan, & Spector, 2012) indicated that the majority of staff had a high sense of their own competence in working with people with dementia. It may be that any improvement such as that found for five staff participants, would not have been statistically significant in an analysis even if it was completed with a full complement of data. If staff measures are included in a follow up study it is recommended that the use of SCIDS is reviewed and consideration given to whether a more granular measure of one aspect of staff development is more suitable.

Involvement of volunteer researchers both relieved and added to pressure points in the study. On one hand it would have been extremely difficult for one person to attend disparately located care homes, avoid biased responses and gather all of the measures at the times they needed to be collected. However, lead researcher time was also needed to carefully think through and deliver the resources, training and processes the volunteers required to maintain the integrity of the project. In a future study, I would emphasise the importance of avoiding missing data within and across scales during researcher training sessions. Overall, I believe the volunteers executed the data collection and reporting extremely well in difficult circumstances.

Attrition.

This study had a very high attrition rate which exposed intervention feasibility issues, methodology considerations and researcher-care home partnership and communication challenges. Despite this, the study was extremely worthwhile as it attempted to address the critical clinical problem of early residency adjustment and outcomes which have not been addressed with an intervention before.

Understanding the intervention weaknesses and strengths allowed for further enhancements and expansion of knowledge of ‘how to get it right’.

One attrition mitigation strategy mentioned in the empirical paper may be to amend the inclusion criteria to people with less severe levels of dementia such as up to Functional Assessment Staging Test (Reisberg, 1987) 6a rather than the 6e level that was used for a future trial. While this may prevent the study being impacted by high rates of participant death and hospitalisation it does exclude a group of new residents from support with relocation adjustment. A separate intervention with a short duration of days rather than weeks could be developed to better meet this cohort’s adjustment needs.

Researcher visits to care homes in the first week of intervention delivery and regular visits undertaken over the duration of the programme may mitigate implementation and attrition difficulties. Visits would aid a better understanding and assistance of staff to overcome implementation and delivery barriers and form part of the study observations. Multiple researchers would be required to accomplish this. Partnership and communication topics are detailed later in this appraisal.

Analysis.

Quantitative analysis. I learnt how to conduct and interpret a mixed model analysis in SPSS which I had not done before. If missing data had not rendered results inconclusive I would have needed to learn about how to account for potential confounds such as length of residency, cultural differences and family involvement (Robson, 2002; Sury, Burns, & Brodaty, 2013) when using this type of analysis.

Qualitative analysis. Thematic analysis was used as it was deemed the most pragmatic, appropriate and flexible approach for systematic management of data with different formats, that also cut across different sources, each of which pertained to different hypotheses or parts of the hypotheses being considered. While flexibility is a strength of thematic analysis, depending on how it is applied, more nuanced data can be missed (Braun and Clarke, 2006). Therefore, if more and consistent data had been collected from families and residents as well as staff, a narrative analysis may have yielded a richer set of results. Language-based approaches such as discourse and conversation analysis were discounted as the language used was less important than identifying and understanding the central ideas. The time scale and resourcing for the research did not support an ethnographic approach.

I learnt that the thematic analysis for a feasibility study is somewhat different from other studies in which the topic is broader and more explorative. The semi structured interview guide would have been greatly improved by having more open questions and fewer questions overall, to elicit richer data from which the themes about feasibility could be derived. Instead there was a constant striving for balance between open questions and acquiring clear responses about specific aspects of the intervention such as SettleIN language and module timings.

Reporting.

Reporting the study outcomes was a juggle between full transparency and avoiding over interpretation. On one hand due to the small sample size, good practice dictates that any promising results indicated by staff during post intervention interviews were dismissed and more weight be given to indications of no benefit and the lack of corroboration with validated measures. While I understand the importance of this practice due to the potential bias involved, I felt myself pulled in different directions. I recognised my own bias towards any positive outcomes and an irritation that the qualitative results were being considered as less important than quantitative results. I doubted whether minimal interpretation would be applied if the qualitative and quantitative results had been reversed, that is, if quantitative results had shown positive outcomes for residents and qualitative results had shown definitive reports of no benefit or adverse effects. I questioned the investment in a mixed method design though acknowledged how influential a well powered study with a low attrition rate would have been where both quantitative and qualitative analysis provided corroboration for results.

Alternative data presentation methods such as those aligned to small-n case experiments, clinical replication series or naturalistic case studies could have been employed. Each of the five individuals who received SettleIN would have been considered their own control. An in-depth look at the uniqueness and complexity of the intervention outcomes and barriers to implementation on a case by case basis may have provided a richer understanding of whether SettleIN worked or not and why (Barker, Pistrang & Elliot, 2002). There were two main reasons why these approaches were not employed in this instance; a) missing data across the agents of staff, resident and family measures for each case varied; therefore, individual graph-based reporting would have been inconsistent across cases, and b) a small n-design and specific resident behaviours of interest were not identified or applied from the outset of the study; reporting it as such may have compounded bias and misrepresented results. If I was undertaking the study again I would strongly consider using a small-n design rather than a mixed method approach as the advantages include collection of rich information from multiple sources and easier, less time-consuming recruitment of participants.

Feasibility and hypotheses.

A final thought regarding study design is that while the central intention of this study was to explore the feasibility of the SettleIN intervention, two out of the three hypotheses emphasised efficacy of the intervention for residents and family. Limited-efficacy testing is only one general area of focus addressed by feasibility studies which usually consider acceptability, demand, implementation, practicality, adaptation, integration and expansion (Bowen et al., 2009). Many of these areas were implicit in the overarching hypothesis that SettleIN would be feasible including; care home uptake, intervention completion rates, time investment, acceptability and practicality of intervention data collection, overall intervention acceptability and ease of use. These were investigated through either quantitative or qualitative methods and reported.

However, the study design would have been better served by explicitly defined feasibility research questions and clarity over how each of these components were to be measured. Two examples include; a) for Acceptability, looking at to what extent was SettleIN judged as suitable, satisfying and attractive to staff with an outcome measures of staff satisfaction and perceived appropriateness, and b) for Implementation, looking at to what extent can SettleIN be successfully delivered to new residents in a defined but not fully controlled, care home context where degree of intervention execution, success or failure of execution, amount and type of resources needed are measured. If I was undertaking the study again, I would narrow the scope of the research to consider specific areas of feasibility and provide clarity over the feasibility questions asked and measures used.

Working with care homes

An important consideration for researchers is being familiar with the latest literature about best practice in conducting research in care homes prior to embarking on a project and particularly before starting recruitment. This project met with many of the common challenges faced by researchers working in care home settings including, time-short staff, participant death and changing organisational and leadership structures (Davies, Froggatt, & Meyer, 2009; Froggatt, Davies, & Meyer, 2009; Luff, Ferreira, & Meyer, 2011). Many recommendations for researchers were missed or deprioritised to accommodate the project timeline. Occasionally the recommendations occurred naturally and unsurprisingly, implementation was most successful in these care homes. Overall, there seemed to be a constant balancing act required between doing what the evidence suggested was most likely to work, with doing what there was time to do.

Partnership and communication.

Development of stronger partnerships with one to two care homes only, may have allowed for recruitment and retention of more participants to follow up stage and a more complete set of outcomes. However, by engaging six care homes I was able to gain insight into how difficult it can be for researchers and care home managers to make time for developing partnerships and to observe the variance in managers' interest in doing so, even when they considered the intervention to be worthwhile. Many other factors appeared to influence partnerships including researcher proximity to geographical location of the care home (and therefore, frequency of attendance at homes across three counties), impending Care Quality Commission inspections and managers' personal and own training commitments.

Managing change to planned intervention delivery such as during unforeseen staff leave was particularly difficult and efforts to adhere to best practice regarding communication were often thwarted (Luff et al., 2011). Some care homes did not respond to contact attempts during the study. This meant it was difficult for the lead researcher to provide support and ascertain SettleIN progress, until after the delivery period had elapsed. By this time, it was also too late to recover intervention delivery due to the participant's length of residency meeting the study's exclusion criteria. On reflection, there were also other occasions in which some care home managers appeared more interested in having the training and certificates on offer and were less committed to delivering the intervention.

If I repeated the study, upfront investment of more time to develop researcher-care home manager partnership and mutual understanding of needs and goals is likely to be one of the most important methods of mitigating recruitment, implementation and delivery difficulties. It is also likely to elicit better communication between managers, staff and researchers and enable discussions and agreements about how unforeseen scenarios that stall or halt intervention implementation can be managed.

Directions for future research

A second well powered study exploring the feasibility of an enhanced SettleIN intervention is necessary and warranted due to the positive feedback that was received during the study and the importance of the topic. A joint or research team resource approach is recommended to help facilitate best practice research and mitigate some of the difficulties already outlined in this appraisal. Inclusion of a control group would also help discern between intervention effects and other factors influencing adjustment.

Future research could also consider the concept that a more effective way of recruiting care home managers and staff and inspiring implementation may be for staff to hear directly from staff. Participants from this study could outline how they incorporated the previous version of SettleIN into their working day and describe the staff benefits they experienced. This could be achieved in person or with the development of a short multimedia presentation. Another suggestion that arose during the consultation phase was to create a multimedia resource for training that might be more accessible to staff than having to attend a scheduled training session about SettleIN. Any multimedia product would need to be subject to intervention development best practice to ensure it too, was appropriate and feasible (Moore et al., 2014).

Summary

While the strengths and importance of the literature review and empirical study may have less emphasis than highlighting learning points in this critical appraisal, I believe the manner in which the studies were undertaken and the output produced, do reflect a clinically valuable and worthwhile contribution to the dementia field. The intervention developed was promising and warrants further enhancement. Furthermore, I have learnt about the feasibility of a lone researcher conducting methodologically rigorous and high quality research and experienced one of the core aims of completing a doctorate.

A common adage when reviewing most research or business projects seems to be that there needed to be more time, more resources or more money and that if one or more of these were granted, the quality of the end result would have improved. I think the adage applies to this study. Research in care homes is a complex activity (Luff et al., 2011) and my project had strengths and weaknesses. I am pleased with what was achieved with the limited time, resources and funding involved and I am most grateful for the support I did receive to make it happen.

Conclusion

This critical appraisal has summarised my main reflections on carrying out the major research project as part of my Doctorate in Clinical Psychology. I have outlined the decisions made in the process of undertaking the work and the methodological and contextual challenges that were faced in the process. I have proposed how I would have conducted the research differently with the knowledge I have now and proposed areas for future research.

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Appendices

Appendix A

MMAT Quality rating criteria and scores (Pluye et al., 2011)

Papers	Qualitative				Quantitative RCTs				Quantitative non-RCTs				Quantitative Descriptive				Mixed method			Rating
	Sources of qualitative data relevant?	Process for analysing data relevant?	Consideration to how findings relate to data collection context?	Consideration to how findings relate to researchers' influence?	Clear description of randomisation?	Clear description of allocation blinding?	Complete outcome data (80% +)?	Low withdrawal/drop-out (< 20%)?	Participant selection bias minimised?	Measurements appropriate?	Participant groups comparable, or differences controlled for?	Outcome data (80%+), response rate (60%+), follow-up rate?	Sampling strategy relevant?	Sample representative of study population?	Measurements appropriate?	Response rate acceptable (60% +)?	Mixed methods research design relevant?	Integration of qual/quant data relevant to research question?	Consideration of limitations associated with this integration?	* , ** , *** or ****
Minematsu (2006)									N	Y	CT	CT								*
Edvardsson et al (2010)	Y	Y	N	N																**
Jablonski et al (2005) [b]					Y	CT	P	N												**
Dobbs et al (2005)									Y	Y	Y	N								***
Grabowski et al (2009)									N	Y	Y	Y								***
Majerovitz et al (2009)	Y	Y	P	N																***
Port et al (2005) [b]	Y	CT	Y	P					Y	Y	Y	Y					Y	Y	CT	***
Reinhardt et al (2014)					N	Y	Y	Y												***
Reinhardt et al (2015)									P	Y	Y	Y								***
Robison et al (2007)	Y	Y	Y	Y	N	Y	Y	Y									Y	Y	Y	***
Stirling et al (2014) [c]	Y	Y	Y	N																***
Strang et al (2006) [b]	Y	Y	N	P																***
Aveyard et al (2006)	Y	Y	Y	Y																****
Bramble et al (2011) [a]					Y	Y	Y	Y									Y	Y	Y	****
Bramble et al (2009) [a]	Y	Y	Y	P													Y	Y	Y	****

(Continued)

Papers	Qualitative				Quantitative RCTs				Quantitative non-RCTs				Quantitative Descriptive				Mixed method			Rating
	Sources of qualitative data relevant?	Process for analysing data relevant?	Consideration to how findings relate to data collection context?	Consideration to how findings relate to researchers' influence?	Clear description of randomisation?	Clear description of allocation blinding?	Complete outcome data (80% +)?	Low withdrawal/drop-out (< 20%)?	Participant selection bias minimised?	Measurements appropriate?	Participant groups comparable, or differences controlled for?	Outcome data (80%+), response rate (60%+), follow-up rate?	Sampling strategy relevant?	Sample representative of study population?	Measurements appropriate?	Response rate acceptable (60% +)?	Mixed methods research design relevant?	Integration of qual/quant data relevant to research question?	Consideration of limitations associated with this integration?	*, **, *** or ****
Caron et al (2005)	Y	Y	Y	Y																****
Cohen et al (2014) [b]									Y	Y	Y	Y								****
Chappell et al (2014)									Y	Y	Y	Y								****
Gladstone et al (2006)	Y	Y	Y	Y																****
Helgesen et al (2012)	Y	Y	Y	Y																****
Johansson et al (2014)	Y	Y	Y	Y																****
Lau et al (2008)	Y	Y	Y	Y																****
Legault et al (2009)	Y	Y	Y	Y																****
Levy-Storms et al (2005)									Y	Y	Y	P								****
Reid et al (2015)													Y	Y	Y	Y				****
Zimmerman et al (2005)									Y	Y	Y	Y								****

Note. Y=Yes, P= Yes (partial), N=No, CT= Can't tell. The score is 25% (*) when QUAL (Qualitative component)=1 or QUAN (Quantitative component)=1 or MM (Mixed methods component)=0; it is 50% (**) when QUAL=2 or QUAN=2 or MM=1; it is 75% (***) when QUAL=3 or QUAN=3 or MM=2; and it is 100% (****) when QUAL=4 and QUAN=4 and MM=3 .

[a] Mixed method study with quantitative and qualitative results reported separately.

[b] Companion paper consulted

[c] Companion paper unpublished in peer reviewed journal

Appendix B

Questionnaire for capturing feedback during stakeholder consultation

SettleIN Validator Feedback Form

Please return the completed form to Janine Hayward by email to [redacted] or post to [redacted]

This brief form is for collecting feedback from reviewers of the SettleIN programme directly or via a telephone interview. Reviewers include; people with dementia, family and other carers of people with dementia, care home managers and staff, community health teams and academics and clinicians experienced in working in the field of dementia.

The first section captures details about you, the reviewer. The second section captures your general feedback about SettleIN. The third section asks for specific role based feedback. Finally the fourth section is for adding any additional comments.

How will your feedback be used? Feedback from all reviewers will be collated and analysed so that improvements to SettleIN may be made. A summary of the feedback received with some individual comments highlighted may be written up for future publication. This will be done without revealing any of your personal details. If you prefer that your anonymised comments be included in the summary only and not individually highlighted in any publication please state this in section four of the form.

Certificates for your Continuing Development Programme
Certificates to acknowledge your involvement in this research are available. Please mark the box indicated if you require a certificate.

YOUR FEEDBACK IS AN IMPORTANT PART OF PROGRAMME DEVELOPMENT/RESEARCH. THANK YOU FOR CONTRIBUTING.

Section 1: About You

Office Use Only- If by telephone; Interview Date:

Name	
Age and Gender (Please circle two)	18-24 / 25-34 / 35-44 / 45-54 / 55-64 / 65+ Male / Female
Occupation	
Email address (for certificate/ answer clarification)	
Employer and place of work	
Total number of years caring/working with people with dementia/in field	

Your role (Please place X to any that are relevant; you may have than one role)

Person with Dementia / MCI ___
Family Carer or other (non staff) carer ___
Care Home Manager ___
Care Home Staff ___
Academic Expert ___
Clinician Expert ___
Other ___ (Please state) ______

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How much of SettleIN have you reviewed? (Please mark X next to category that best represents your review) – ALL & ANY ARE HELPFUL!

Management Manual and Staff Workbook ____
Management Manual only ____
User Guide & Workbook only ____
One Page Overview in Manual ____
One Page Overview and Modules ____
Modules Only ____
Other (Please state) ________________________

Do you require a Certificate?	Yes / No (please delete one)

Section 2: General Feedback about SettleIN

How appropriate and realistic is SettleIN? Please put X in box that best represents your view

Appropriate (in this context refers to suitable and correct)

Completely Inappropriate	Slightly inappropriate	Neither Appropriate or Inappropriate	Somewhat Appropriate	Completely Appropriate

Realistic (in this context refers to for people with dementia)

Completely Unrealistic	Slightly Unrealistic	Neither Realistic or Unrealistic	Somewhat Realistic	Completely Realistic

Please add any relevant comments regarding appropriate and realistic here and in particular what would have to change to make SettleIN more appropriate/realistic?

How understandable is the SettleIN Manual/Core Template and language used? Please put X in box that best represents your view

The Manual (Overall)

Very difficult to understand	Difficult	Neither Easy or Difficult	Easy	Very easy to understand

Is the language used easy to follow? Yes / No (please delete one)

Is there a section or page that needs to be clearer? Yes / No (if Yes, please state)

Were there any words that were difficult to make sense of? Yes / No (If yes, please state)

What do you like most about the SettleIN programme?

What do you like the least about the SettleIN programme?
N.B if the same as above please state 'as above'

How feasible do you think it will be to deliver SettleIN and what obstacles to delivery do you forsee? Please put X in box that best represents your view

Feasibility to deliver

Completely unfeasible	Slightly unfeasible	Neither Feasible or unfeasible	Somewhat Feasible	Completely Feasible

Please comment on what obstacles you can forsee arising when delivering SettleIN and any changes you suggest be made to SettleIN to make it more feasible for delivery.

Section 3: Role Specific Feedback

If you are a person with dementia (PwD) please answer questions 1, 3
If you are a family carer / other (non care home) staff carer (FC) please answer questions 1, 4
If you are a care home manager (CHM) please answer questions 1, 2, 5, 6
If you are care home staff (CS) or other staff e.g. OT please answer questions 1, 2, 5
If you are an expert academic or clinician please answer questions 1, 2, 5

1
ALL

Thinking about your main role, how acceptable is the SettleIN programme to you? Please put X in box that best represents your view

Acceptability

Highly Unacceptable	Unacceptable	Neither Acceptable or Unacceptable	Acceptable	Highly Acceptable

If you have chosen unacceptable or highly unacceptable please state why and what would have to change to make in the programme or manual SettleIN acceptable? (If the why is the same as the 'least liked element' above, please state 'as in question X')

If not already stated, Please say how SettleIN would need to be changed to make it acceptable or more acceptable to you.

2 CHM CS	Overall, how does SettleIN compare to Care As Usual? Is it totally different or similar and how?

3 PwD	Thinking about your experience of the first few weeks in a care home is there anything you received or would have liked to have done/received that is not included in SettleIN? If you have yet to move into a care home is there anything you would like to do/receive in your first few weeks once you do move in to help you settle in that is NOT included in the SettleIN programme? Did the **Information for Residents** sheet in the Manual (page 17) make sense? Yes / No (please delete one). Do you think it is helpful for a new resident? Yes / No (please delete one). Why?

4 FC	Thinking about your experience (or consideration) of your loved one / PwD's first few weeks in a care home is there anything that you did/ did not receive or would like to have happen that is not included in SettleIN? Does SettleIN make your involvement clear? Yes / No (please delete one and comment) Did the **Information for Family and Carers** in the Manual (page 18 and 19) make sense? Yes / No (please delete one). Do you think they are helpful? Yes / No (please delete one). Why?

5 CHM CS	Thinking about the four SettleIN modules, do you think the estimated timings are accurate? Yes / No (please delete one and comment) Do you think the timings are helpful or do you think they would be off putting to a care home manager who may be considering trialling SettleIN? Helpful/ Unhelpful (please delete one). Please explain why. Did the **Information for Residents and for Family and Carers** in the Manual (pages 17 and 18 to 19) make sense? Yes / No (please delete one). Do you think they are helpful? Yes / No (please delete one). Why?

6 CHM	In your Care Manager role would you be willing to make staff available to follow the SettleIN programme? Yes / No (please delete one) If different from any previous answer, please explain why Would you be happy to support and supervise staff undertaking SettleIN? Yes / No (please delete one). Please explain why.

SettleIN Validator Feedback Form v0.4 29-8-15

Section 4: Please add any other comments you have about SettleIN

THANK YOU

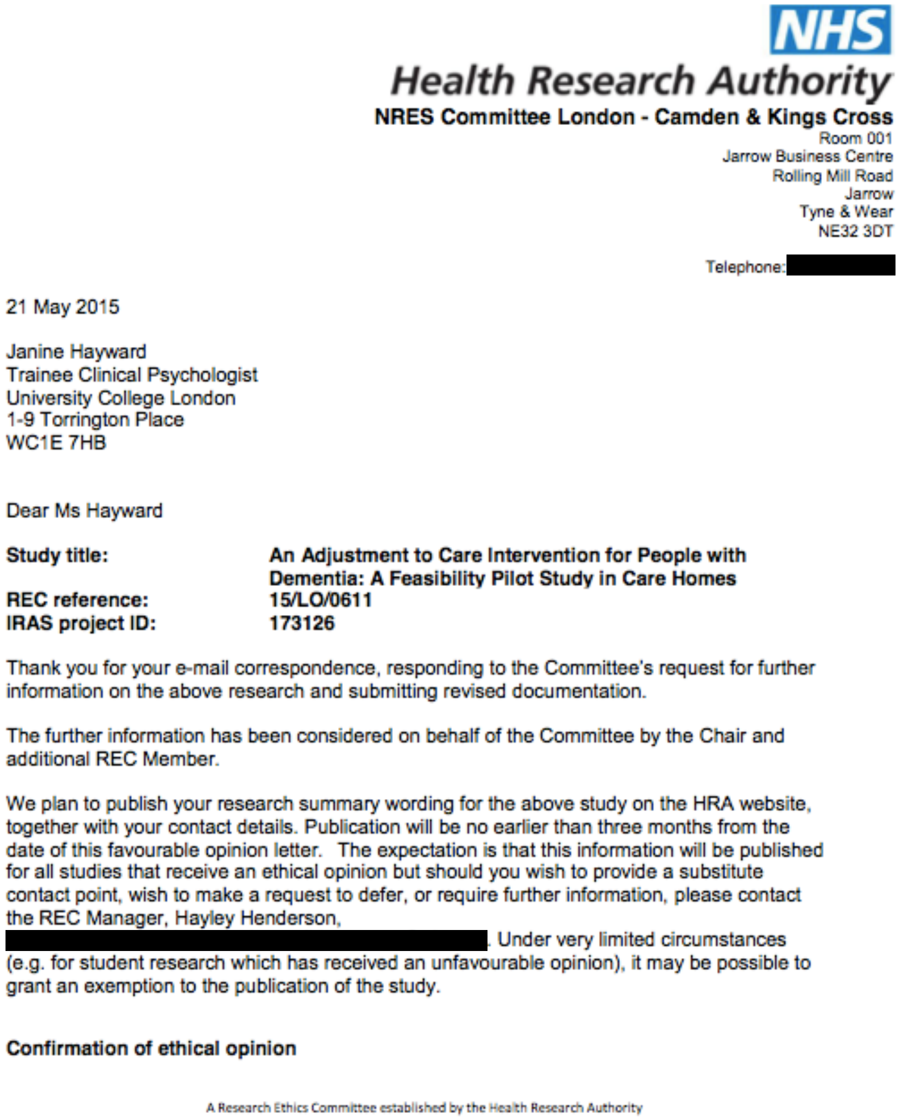
Please return the completed form to:

Janine Hayward
by email to [redacted]

or post to
Janine Hayward,
[redacted]

Appendix C

Ethics Approval



NHS
Health Research Authority
NRES Committee London - Camden & Kings Cross
Room 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne & Wear
NE32 3DT

Telephone: [redacted]

21 May 2015

Janine Hayward
Trainee Clinical Psychologist
University College London
1-9 Torrington Place
WC1E 7HB

Dear Ms Hayward

Study title:	**An Adjustment to Care Intervention for People with Dementia: A Feasibility Pilot Study in Care Homes**
REC reference:	**15/LO/0611**
IRAS project ID:	**173126**

Thank you for your e-mail correspondence, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and additional REC Member.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Hayley Henderson, [redacted]. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [redacted] The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [REC Cover letter]	v1.0	05 March 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [From: 01.08.14 - 31.07.15]	v1.0	14 July 2014
GP/consultant information sheets or letters [GP Information letter]	v0.3	20 May 2015
Interview schedules or topic guides for participants [SettleIn Interview Schedule]	v0.2	13 May 2015
Letters of invitation to participant [Letter to nominated consultee]	v0.2	27 February 2015
Letters of invitation to participant [Personal consultee invitation]	v0.3	13 May 2015
Letters of invitation to participant [Letter to nominated consultee]	v0.3	13 May 2015
Letters of invitation to participant [Letter to personal consultee]	v0.3	13 May 2015
Other [150201 Insurance Letter 18.03.15]	12	09 August 2011
Other [SSE agreement letter]	0.2	22 March 2015
Other [SSE agreement letter]	v0.3	13 May 2015
Other [15.LO.0611 Response to REC email 15.05.15 notice]	v0.1	20 May 2015
Other [UCL Research Incidents and Complaints v4 Jul2014]	v4	20 May 2015
Participant consent form [Resident Participant consent]	v0.3	13 May 2015
Participant consent form [Staff consent]	v0.2	13 May 2015

Participant consent form [Care home manager consent]	v0.2	13 May 2015
Participant consent form [Nominated consultee declaration]	v0.3	13 May 2015
Participant consent form [Personal consultee declaration]	v0.3	13 May 2015
Participant information sheet (PIS) [Resident Participant PIS]	v0.5	20 May 2015
Participant information sheet (PIS) [Staff PIS]	v0.5	20 May 2015
Participant information sheet (PIS) [Care home manager PIS]	v0.5	20 May 2015
Participant information sheet (PIS) [Nominated consultee PIS]	v0.5	20 May 2015
Participant information sheet (PIS) [Personal consultee PIS]	v0.5	20 May 2015
Participant information sheet (PIS) [Resident Assent and Witness]	v0.5	20 May 2015
REC Application Form [REC_Form_21052015]		21 May 2015
Referee's report or other scientific critique report [Departmental Review and Approval]	v1.0	26 January 2015
Research protocol or project proposal [Research Protocol]	v3.0	13 May 2015
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [DrAimeeSpector-CI-CV]		04 February 2015
Summary CV for student [Janine Hayward 2015_CV]		
Summary CV for supervisor (student research) [DrAimeeSpector-AcademicSupervisor-CV]	v1.0	18 March 2015
Summary CV for supervisor (student research) [CV - Cliva Ballard]		
Validated questionnaire [Summary of questionnaires and measures]	v1.0	18 March 2015
Validated questionnaire [Fast]	v1.0	20 March 2015
Validated questionnaire [QOL-AD]	v1.0	20 March 2015
Validated questionnaire [SWC-EOLD]	v1.0	20 March 2015

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.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

15/LO/0611	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp [redacted]

Mrs Rosie Glazebrook
Chair

[redacted]

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*
Copy to:	*Mr Dave Wilson, Joint Research Office UCL*
	Dr Aimee Spector, University College London

[redacted]

Appendix D

Information Sheets and Consent forms

Information sheet and consent form for care homes

Information sheet and consent form for residents

Information sheet and consent form for families

Information sheet and consent form for staff

Information sheet for General Practitioner

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

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

SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study
(Doctoral Student Study)

Version …0.5………, Date …………………

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 Janine Hayward, as part of her 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 each newly admitted resident. 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 agree for the care home to be a research site for this project you will be asked to do the following:

1. 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 at 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 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 (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 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 t 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 (15/LO/0611).

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 [redacted] at the Joint Research Office, UCL, Gower Street, London WC1E 6BT.
Telephone: [redacted].

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 Researcher, Janine Hayward or the Chief Investigator Dr Aimee Spector, on [redacted], or by writing to the address on the letterhead.

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

Yours

Janine Hayward
Trainee Clinical Psychologist

Dr Aimee Spector	Professor Clive Ballard
Senior Lecturer in Clinical Psychology	Professor in Age Related Diseases
University College London	Kings College London

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

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Participant (Care Home) identification Number:

Name of Researcher:

Title of project: SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study

CONSENT FORM

Please ***initial*** box

1. I confirm that I have read and understand the information sheet dated [date] 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 Participant	Date	Signature
Name of Person taking consent	Date	Signature

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

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UCL

PARTICIPANT INFORMATION SHEET

Version …0.5………, Date ……………

Study Title: SettleIN – A tool to help people with Memory and/or Communication Problems quickly and successfully adjust to their new home: 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. The study will be conducted by Janine Hayward, 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 designed for people with memory and communication problems to adjust and adapt to living in new accommodation. It involves helping you, your carers and staff who look after you, choose the best activities to support your sense of well being while you become familiar with your new surroundings and make them a 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?

In addition to your usual care, a member of staff (and/or a trainee psychologist) or your carer will spend extra 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.

On three occasions spread out over two months, a research assistant will ask for your help to complete short questionnaires to check how the new programme is going.

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?

If you do decide to take part in the study, we hope that you will adjust and adapt quickly to your new home, enjoy a higher quality of life sooner than you may have done after your move and ultimately thrive in your new home.

Research has shown that when people are provided with support for healthy adjustment to their new accommodation, their quality of life improves and they are less likely to experience unwanted reactions such as anxiety and depression, although we cannot promise this.

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?

We hope that the staff who provide care for you will continue to assess and treat any pain you may have using the skills and knowledge they have learned from the training they get.

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 [redacted] at the Joint Research Office, UCL, Gower Street, London WC1E 6BT. Telephone: [redacted].

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 Janine Hayward, a Trainee Clinical Psychologist who is 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:

Janine Hayward
[redacted]

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

Dr Aimee Spector
[redacted]

Thank you for thinking about taking part in this research study

Yours

Janine Hayward

Trainee Clinical Psychologist

Dr Aimee Spector	Professor Clive Ballard
Senior Lecturer in Clinical Psychology	Professor in Age Related Diseases
University College London	Kings College London

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PARTICIPANT CONSENT FORM

Study Title: SettleIN – A tool to help people with Memory and/or Communication Problems quickly and successfully adjust to their new home: An intervention development and feasibility pilot (student study).

Name of Researcher: Janine Hayward

Participant Number:

	Please initial boxes
1. 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 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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INVITATION TO ACT AS PERSONAL CONSULTEE

Study Title: SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study (Doctoral Student Study)

Participant Number:

Researcher: Janine Hayward

I think that my partner, friend or relative may **NOT** like to take part in the project.	I agree with this statement Signed
I think that my partner, friend or relative may be interested in taking part and I would like to discuss this with the researcher. I have provided a contact number and the times I can be contacted below.	I agree to being contacted further about the study Signed
I think that my partner, friend or relative 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 Janine Hayward at …………………………………….. care home.

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Study Title: SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study

PERSONAL CONSULTEE INFORMATION SHEET

Version …0.5………., 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 – A tool to help people with dementia quickly and successfully adjust to their new home: 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?

The 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 study the effects of the intervention on adjustment in residents, we would do the following:

1) The principal researcher will look at participant's medical records to obtain details about any relevant diagnoses, medication, health complexities and pre-admission 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 participating in this research will lead to a direct benefit to patients through improved individualised support of healthy and successful adjustment to their new location in a care home, although this cannot be guaranteed. If transition to a care home and poor adjustment is a problem for people then providing support for successful, healthy adjustment is likely to enhance their quality of life. 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.

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 researcher, please fill in the attached 'Invitation to Act as Personal 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 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 researcher.

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 researcher, 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?
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 [redacted] at the Joint Research Office, UCL, Gower Street, London WC1E 6BT. Telephone: [redacted].

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 would like to know more, please contact the Researcher, Janine Hayward on [redacted] or [redacted]. Alternatively you can contact the Chief Investigator Dr.Aimee Spector, on [redacted], or by writing to the address on the letterhead.

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
[redacted]

Thank you for thinking about helping us with this research study

Janine Hayward
Researcher/Trainee Clinical Psychologist

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

Professor Clive Ballard
External Academic Supervisor
Professor Age Related Diseases
Kings College London

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PERSONAL CONSULTEE DECLARATION

Study Title: SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study (Doctoral Student Study)

Participant Number:

Researcher: Janine Hayward

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

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

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SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study (Doctoral Student Study)

Information for staff about the research

Version …0.5……., Date ………………

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 Janine Hayward, as part of her 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.

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?

If you agree to take part you will be asked to do the following:

1. Complete some questionnaires about yourself (demographic information, qualifications, job details etc.) and your knowledge and attitudes towards dementia and pain in dementia. These will take approximately 10 minutes and will be paper and pen based.

2. 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.

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. 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 (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 15 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?
The potential benefits for you are 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 you to provide the best care possible for your 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 [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 [redacted] at the Joint Research Office, UCL, Gower Street, London WC1E 6BT. Telephone: [redacted].

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 Researcher, Janine Hayward or the Chief Investigator Dr. Aimee Spector, on [redacted], or by writing to the address on the letterhead.

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

Yours

Janine Hayward
Trainee Clinical Psychologist

Dr Aimee Spector	Professor Clive Ballard
Senior Lecturer in Clinical Psychology	Professor in Age Related Diseases
University College London	Kings College London

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

Participant (Staff) identification Number:

Name of Researcher:

Title of project: SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: A feasibility pilot study

CONSENT FORM

Please ***initial*** box

1. I confirm that I have read and understand the information sheet dated 08/05/14 (version 1.2) 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
________________	________________	________________
Name of Person taking consent	Date	Signature

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

Department of Clinical, Educational and Health Psychology

University College London
Gower Street

London

WC1E 6BT
Phone: 07879405138
Email: [redacted]

Date: ………………….

GENERAL PRACTITIONER INFORMATION SHEET

Study Title: SettleIN – A tool to help people with dementia quickly and successfully adjust to their new home: 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 Janine Hayward, Trainee Clinical Psychologist, as part of her training at University College London. She is 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. The 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:

1) The principal researcher will look at participant's medical records to obtain details about any relevant diagnoses, medication, health complexities and pre-admission care planning.
2) Residents (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.

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

Janine Hayward
Trainee Clinical Psychologist

Appendix E

Semi Structured Interview Guide

The interview: PLEASE MAKE SURE THE RECORDING DEVICE IS SWITCHED ON

Into tape/on notes record;

Date and Own (interviewer's) Name,

Participant's number (as pre confirmed with the principle researcher) or if don't have this, please state the participant's initials and the initials of the location and care home e.g. Oak House in Watford would be WHO (W=Watford, OH=Oak House).

General Questions (Warm Up)

This section focussed on opening the interview, encouraging the respondent to talk and gaining the general impression the staff participant had about the SettleIN programme.

1. Overall, how easy/difficult was SettleIN to use?
2. Can you tell me about your best moment when using SettleIN or when completing one of the SettleIN activities with a resident? ("What did that feel like, when you were…?)
3. What did you like about SettleIN? Why?
4. What did you dislike about SettleIN? Why?

Feasibility

This section focussed on how possible and practical the SettleIN programme is for care staff to use and deliver easily and aims to identify any obstacles (and solutions).

5. Thinking about the very beginning of SettleIN, the needs assessment phase - how easy/difficult was it to;
    a. Work out with the resident what they felt about living in the care home at that point in time?
    b. select which SettleIN modules would be included in each resident's programme?
6. Thinking about the SettleIN modules,
    a. which aspects did you find easiest to deliver? Why?
    b. which aspects did you find most difficult to deliver? Why? Did you adapt them in anyway?
    c. how did you find the estimated timings next to each activity? Helpful? Why?
7. Overall, how does SettleIN compare to Care as Usual? Is it similar or totally different? In what way?

SettleIN language, detail and design

This section focussed on how understandable the language and instructions were in the SettleIN manual and workbook. The secondary aim was to check SettleIN's suitability for use with care staff whose first language may not be English.

8. Overall, how well did the author's guidelines and instructions in the manuals make sense?
9. How would you describe the level of detail the author used? Did the author get the level of detail right?
10. How would you describe the length of the manual? Did the author get the length right?
11. How would you describe the language the author used? Was it easy to understand?
    a. Was there anything that wasn't expressed clearly enough? If yes, which bit? Do you have any ideas about how to make it clearer?

Acceptability to staff and managers

This section focussed on how suitable staff and managers determine SettleIN to be for inclusion in care home processes and services.

12. Would you support the introduction of SettleIN as a standard part of admission processes? Why? / Why Not? (If Interviewee is a Manager, would you be willing to support and supervise staff undertaking SettleIN?, Why ? Why Not?)
13. If you could change one aspect of SettleIN to make it more practical what would that be and how would you change it?
14. If this change was made would you argue for the adoption of SettleIN? Why? Why Not?

Impact on Residents and You

This section focussed on how residents, staff and families responded to SettleIN.

15. During or after completing SettleIN with residents, did you notice any changes in their;
    a. Behaviour?
    b. Cognition (memory / thinking)?
    c. Mood?
16. How did other staff respond to SettleIN?
17. How did families/external carers respond to SettleIN?
18. How would you describe your overall experience of using SettleIN? Was there any positive or negative impact on you?

Confirmation and Multiple Choice Summary (quantitative questions)

This section focussed on closing the interview by capturing a summary and the degree to which a staff member or manager finds SettleIN feasible as well as any final comments the staff carer/manager may have.

19. Overall, how appropriate is SettleIN for both residents and staff? Please chose from:

Completely Inappropriate	*Slightly inappropriate*	*Neither Appropriate or Inappropriate*	*Somewhat Appropriate*	*Completely Appropriate*

20. Overall, how feasible is SettleIN (i.e. possible and practical to do easily or conveniently)? Please chose from:

Completely unfeasible	*Slightly unfeasible*	*Neither Feasible or unfeasible*	*Somewhat Feasible*	*Completely Feasible*

21. Thinking about your specific role (care staff, team lead/manager, or family) how acceptable is the SettleIN programme to you personally? Please chose from:

Highly Unacceptable	*Unacceptable*	*Neither Acceptable or Unacceptable*	*Acceptable*	*Highly Acceptable*

22. Overall, how easy or difficult was the Workbook and Manual to understand? Please chose from:

Very difficult to understand	*Difficult*	*Neither Easy or Difficult*	*Easy*	*Very easy to understand*

23. Finally, Is there any other comment you would like to make about SettleIN or the research?

PLEASE THANK THE INTERVIEWEE.

Appendix F

Measure: Index of Relocation Adjustment (Prager, 1986)

		COMPLETELY DISAGREE (0)	**DISAGREE (1)**	**AGREE (2)**	**COMPLETELY AGREE (3)**
					
1	I have found a niche or place for myself here				
2	I usually feel in control of events and situations that affect my life here				
3	Since coming here I have often felt like an outsider who doesn't quite belong				
4	I find myself unable to do many of the things which I had hoped to do here				
5	I don't feel comfortable with my present life situation				
6	I feel a sense of personal fulfillment in my life here				

Note. Items 3, 4, and 5 are reverse items. Scores range from 0 to 18. Higher scores indicate greater adjustment. Faces have been added for ease of use by residents.

Appendix G

Themes and codes derived from the qualitative data presented by hypothesis

Hypothesis 1: SettleIN will be feasible for care home staff to implement and deliver

Open Codes	Axial Codes	Selective Codes
Created Bonds with Residents Increased staff confidence Handle difficult situations Inter-staff communication Positive impact on staff Sense of achievement Should do - teaches staff Staff enjoyed using SettleIN	Staff enjoyed using SettleIN and experienced a diverse array of benefits	Staff found SettleIN beneficial, better than care as usual, appropriate and easily integrated into care practice
Continuity of life for Resident Feeling good about the resident Gaining insight into resident's life It was a surprise Get to know the Resident Nothing disliked SettleIN gave residents piece of mind	An array of factors most liked about SettleIN all pertained to getting to know the resident or taking pleasure in a benefit for the resident	
Comparison with care-as-usual Different Similar Similar and different Feasible from staff perspective SettleIN was easy to use Did throughout the day Recording at time of CAU Easy to use	SettleIN is similar and different to CAU, and able to be incorporated into a normal working day	
Duration of Programme Language Difficult Easy Modules Content Acceptable and appropriate Too many questions Difficult - Recording sheets Easier/harder Modules Timings Overall Structure Understanding SettleIN	Overall SettleIN design is acceptable, appropriate, and easily understood; some minor improvements are recommended	
Contacting/feedback from family Depends on resident Good for some and not others Resident being hard to talk to Resident can't learn new things Resident memory/confusion Staff - time short Staff - short staffed Staff resident reallocation Managerial support Staff and Cultural Barriers	Barriers to SettleIN delivery and success; lack of family support, individual resident differences and where SettleIN was not delivered, a lack of staff time and continuity	SettleIN was harder to implement in some conditions and difficult to deliver with some residents

Note. CAU=Care as usual

(Continued)

Hypothesis 2: People with dementia will experience and retain an improved mood and higher quality of life after having completed SettleIN.

Open Codes	Axial Codes	Selective Codes
Improved behaviour Improved cognition Improved memory Improved mood Increased engagement and involvement Make connections and develop trust People become familiar Resident needs were met - PCC Stimulating-Challenging for Resident Surroundings become familiar	Staff and family observed at least one positive change in either resident behaviour, mood and cognition for each resident in receipt of SettleIN	Staff perceive that some residents experience benefits while other residents do not; observed not always recognised?
Invasion of privacy No change in behaviour No change or worsened mood No improved cognition or memory	Staff reported no significant changes for some residents	
Resident reports	Resident reports varied	

Note. PCC= Person centred care

Hypothesis 3: Family carers will experience higher satisfaction with care after their relative has completed SettleIN.

Open Codes	Axial Codes	Selective Codes
Family involvement Family satisfaction with programme	Families interest varied, interested appear pleased	*Not enough data to draw on*

Other Codes and Themes: How to improve SettleIN

Open Codes	Axial Codes	Selective Codes
Creating games for reluctant residents If two staff - same shifts Improving language and content Layout of recording sheets Planner and structure Condense - Split Weekly rather than daily structure Reduce repetition of activities	A small number of minor changes recommended, simplification proposed	Simplify and reduce dependency on family
Mitigating family contact difficulties	dependency on family	

Appendix [redacted]

[redacted]