DETAILED PROJECT DESCRIPTION
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A multi-site evaluation of the Person, Interactions & Environment (PIE) programme to improve person-centred care for people with dementia admitted to acute hospital wards.

Co-applicants:

Young J, Woolley R, Godfrey M, Brooker D, Surr C, Hoyle J, Hood C, Manley K, Arrojo F, Padilla-Lamb A.

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TITLE: A multi-site evaluation of the Person, Interactions & Environment (PIE) programme to improve person-centred care for people with dementia admitted to acute hospital wards.

AIMS AND OBJECTIVES

The overall objective is to implement and evaluate the PIE tool and linked change process (PIE programme) to improve person-centred care for people with dementia in general hospital wards.

PIE was developed as part of a 3 year research project for use in a national audit of care received by people with dementia in general hospitals (England and Wales). The qualitative observational findings from the PIE audit (105 wards, 43 hospitals) identified what currently exists in terms of care quality and what needs to be in place to improve person-focused communicative ward practices. Raising staff awareness of the impact of what they do on people with dementia through practice observation was identified as being important for facilitating change, so long as there are mechanisms in place to support communicative practices within a proactive ward based approach – individual staff cannot by themselves deliver person-centred care. Action plans to improve person-centred care judged to be realistic and achievable for NHS Trusts to implement were identified in each participating hospital. However, translating action planning at ward level to effect organisational change through the PIE change process, and the systems and mechanisms required to support and sustain it have not been tested; and neither has the PIE programme‟s impact on the care experience of patients, their families/ caregivers and staff, or on patients‟ health outcomes.

The proposed research will implement the PIE programme as a longer-term strategy in five NHS Trusts (11 wards)[1] over 18 months to develop person-focused communication practices and to explore how or whether this actually effects change at organisation, practice and patient levels. It is hypothesised that person-focused communicative practices will lead to improvements in person-centred care and associated health outcomes for people with dementia. The research questions are:

1. Does the PIE programme change ward staff‟s understanding and awareness of person-centred care for people with dementia?
2. Does the process of change initiated through the PIE cycles of observation, action planning, action and review change team members practices and behaviour in ways that are consistent with person-centred care over 18 months?
3. How does the process of change occur? What are the factors that facilitate or hinder change?
4. Is there evidence that the PIE programme is effective in improving care for people with dementia admitted to acute wards, as experienced by those patients and/ or observed by their relatives/ caregivers?
5. Is there preliminary evidence of effectiveness of the PIE programme in improving organisational and clinical outcomes for people with dementia?

The outcome of the proposed study will be an evidence-based tool and manual, including training materials and generalisable albeit flexible implementation process (PIE programme) designed to enhance person-centred communication and care for people with dementia in acute hospital wards with wide applicability across the NHS.

BACKGROUND

Improving general hospital care for people with dementia has been identified as a priority in the Ministerial Advisory Group on Dementia Research (MAGDR) recommendations and forms Objective 8 of the National Dementia Strategy (England; 1) and Target 2 of the 1000 Lives Plus campaign for Wales (2). There is ongoing concern for the necessity to support such change (3-9). Dementia has a prevalence of at least 25% in general hospitals (10). Patients with dementia – primarily older people - are highly susceptible to insensitive care (11-13) as complex needs in relation to their memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement (14) are often unrecognised and unaddressed. They are at high risk of unintended adverse events such as delirium, falls and inappropriate prescription of medication that contribute to poorer health outcomes including greater mortality and loss of independence, with resource consequences of increased length of hospital stay and new care home admissions (10,15-17). A national survey of carers of people with dementia (n=1,291) conducted by the Alzheimer‟s Society found that key areas of dissatisfaction were lack of understanding and recognition of dementia by staff, not being helped to eat and drink, little

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[1] An elderly care and orthopaedic ward in each Trust and an additional ward with 13 beds for people with dementia in one Trust, comprising the elderly care directorate at that hospital site.

stimulation and social engagement and insufficient involvement with decision making (10). Approximately half of respondents reported further deterioration in behavioural and psychological symptoms for the person with dementia and adverse effects on their general physical health unrelated to the medical condition.

Qualitative research conducted from their perspective illuminates that being in hospital is generally distressing and difficult for people with dementia because they do not know what is happening and are often ignored by staff (11). Older people and their families consistently place high value on hospital care which promotes good interpersonal and personalised relationships between patients and staff, viewed as being particularly important for people with impaired cognition/ communication difficulties (18,19). However, interactions tend to be dominated by the delivery of physical care according to a ward based routine rather than being individualised (11) and range from interactions in which both parties participate on relatively equal terms to those which are initiated, dominated and controlled by staff (12). In addition to uncertainty and worry about their future or recovery from the acute illness (11,13), being in an unfamiliar, busy ward is particularly challenging for people with dementia and also has the potential to engender feelings of anxiety, worthlessness, restlessness or agitation, such as attempts to leave the ward to a perceived place of safety (13). The PIE observations carried out in 105 wards, 43 NHS Trusts with 608 patients as part of the national audit of care received by people with dementia in general hospitals (20) adds considerably to this evidence base, and is the only large-scale qualitative acute based study to date of which we are aware. The findings provide robust evidence of the importance of person-centred engagement between staff and people with dementia and enabled a clear definition of the ward systems that need to be consistently in place to support these practices (such as openness to engage and knowledge of the patient as a person). This was demonstrated to be vital not only for addressing patients" social and emotional needs (such as to help people feel significant, included, comfortable, reassured and safe in an unfamiliar environment) but simultaneously to help facilitate their acute care recovery (such as encouraging participation in personal care, consultations, rehabilitative activities and eating and drinking). Only 5 wards provided evidence of exemplary person-focused practices being in place more often than not, illustrating that this way of working is possible yet rare.

Current hospital care systems and processes appear ill-equipped to cater adequately to the „caring" nature of the work. To simultaneously address clinical and care needs, significant shifts are required in organisational culture and staff practices (19) if even basic standards are to be met (21,22).While front-line staff are motivated to provide compassionate care for people with dementia, they also require clear leadership, training and support to be able to do so and to enhance their experience of caring in what may be a demanding environment (6,19,23). Person-centred care has been specifically identified as a key factor for upholding dignity in care (24), is a major component of quality acute care for people with dementia (10-13) and forms one of the key Principles of Nursing Practice recently developed by the RCN (25). Despite being prioritised in the NSF for older people (26,27), there is a lack of methods to help ward teams practically implement person-centred care or to provide evidence of improvement in outcomes for older patients (28-30) or people with dementia (31,32). The person-centred nursing framework (29,33) is the most up-to-date conceptual framework available to guide practice. The proposed study would add to the evidence base of how person-centred care for people with dementia might be implemented by staff on NHS acute wards, following observations of patient experiences and using the conceptual framework for person-focused communication developed as a result of the PIE audit. This would nevertheless have wider applicability to the quality of acute care for older people in general.

NEED

The national audit of dementia care in general hospitals (England and Wales) was commissioned by the Healthcare Quality Improvement Partnership (HQIP) coordinated by the Royal College of Psychiatrists. Preliminary findings from the "core audit", comprising an organisational checklist and review of 40 case notes per site, were reported in December 2010 (34). The audit achieved high participation (89% of eligible hospitals, 99% of Trusts/ Health Boards) in recognition from NHS Trusts that the care of people with dementia is a highly important area for quality improvement. Sadly, the core audit found sub-optimal care standards in many areas which demonstrate lack of appropriate person-centred dementia care e.g. poor assessment of mental state and lack of carer involvement. The PIE tool for observing care was designed as part of the "enhanced audit" used in 55 sites (145 wards) in 2011 (maximum possible within funding constraints). The findings, reported in December 2011 (20), provide further substantive evidence of the extent to which NHS acute Trusts are falling short of providing acceptable care. They reinforce the requirement for currently deficient practices for people with dementia to be overcome through well-informed, organisationally embedded and sustainable systems for promoting person-centred care (35). These issues are not likely to be overcome quickly and will therefore retain sustained interest from the NHS in the future.

Observation is particularly helpful for capturing the experiences of people with dementia as they often cannot reliably self-report, and thereby for informing person-centred practice development initiatives or audit cycles (36). However, there are no other observational tools adapted for use specifically for people with dementia in acute care. Although a literature review identified several potential candidate tools, none were readily applicable: not being dementia-specific (e.g. 37,38); not tailored for use in the acute setting; or overly complex or resource-intensive (e.g. Dementia Care Mapping; 39). A Dementia Care Mapping derivative, the Short Observational Framework for Inspection (SOFI 2), is currently used by the Care Quality Commission in acute hospital settings to evaluate the experience of care from the perspective of the person with dementia (mood, engagement and quality of staff interactions) (40). However, this is only available for use in the context of regulation, not by ward teams. PIE was therefore developed, pre-piloted and refined specifically for acute hospital wards, as a qualitative observational method capable of describing the care experience of patients with dementia and as a means to identify and action specific changes required in staff practices and systems so that they become more person-centred. PIE involves hospital staff carrying out real-time observations of approximately 6 patients over the course of four hours, following a one day workshop, to help raise staff awareness and inform ward action plans.

PIE data for the national audit showed considerable variability between wards in the same Trust in the degree of person-centred care observed, suggesting lack of evidence of a consistent hospital wide culture. Most wards provided evidence of isolated "pockets" of positive, person-centred practice by individual staff members or in certain elements of care (e.g. giving explanations consistently to patients but not knowing the patient as a person). Although good quality acute care from the perspective of people with dementia is person-centred, there is no current consensus on its definition and a lack of tools for measurement or implementation in clinical settings (32,41). As McCormack and colleagues (41) argue "Although the idea of person-centeredness is well understood at a basic level, the challenge is often recognising it in practice. We might think we are delivering care that looks like one thing, but in reality it is quite another." It has become a tokenistic term (41). Qualitative analysis of the national PIE findings confirmed considerable lack of clarity in the way many practitioners currently understand person-centred care e.g. defining this as drawing curtains back for a patient or as being kind and courteous. The findings from the PIE audit relating to what was working particularly well in Trusts enabled an operational definition of "person-focused communication" in relation to people with dementia in acute wards. This has potential to be used to inform an implementation programme, which requires only minor further pre-preparatory work (to sharpen the tool and accompanying learning and development materials). (See ‚additional information section').

Supporting other current research (19,41), we suggest the aim for acute wards should be to gradually move from a position of a predominantly task-focused culture, in which pockets of person-focused practice are observed, to the reverse. The proposed study would help to inform how this might be achieved. Although wards derived action plans from PIE it is not known how or whether these have actually been enacted (other than positive anecdotal evidence). If PIE is to be used to effect change, this requires an understanding of how patient observations can be most effectively and reliably translated into ward and organisational action planning. While the process of undertaking observations, and the knowledge derived from them, is potentially a powerful method for identifying practice change, knowledge itself is insufficient to effect and sustain change (42-44) and attention is increasingly directed at implementation processes: "a set of activities designed to put into practice an activity or programme of known dimensions" to achieve this. Key factors influencing the implementation of evidence and guidelines into practice include the context of care (linked to culture, leadership and evaluation), the presence of skilled facilitation in the workplace (45) and systems and mechanisms for embedding practice change into routine care (42). Effective person-centred care should empower staff and enhance their experience of caring, improve the quality of observed patient experiences and patient and carers perceptions of care quality, reduce behavioural and psychological symptoms of dementia and ultimately improve clinical and organisational outcomes. The widespread adoption of tailored multi-faceted interventions that address individual needs (which the PIE programme proposes) should also help to reduce adverse events (e.g. falls and delirium) as serious hospital acquired complications and associated costs (46). The findings should have wider applicability to other NHS organisations as the issues identified as requiring action across Trusts were remarkably similar. Several sites have requested further use of the tool following national audit, reflecting the on-going high degree of interest in its development.

METHODS

The research questions posed in this study address process and outcomes of the PIE programme (intervention and implementation strategy) at several distinct levels. These relate to:

a) knowledge and understanding of the meaning and content of person-centred care in the specific context of acute hospital care among ward staff individually and collectively;

b) features of implementation processes and mechanisms that facilitate positive change in staff‟s patterns of behaviour, team practices and ward systems toward improving person centred care in people with dementia over a period of time;
c) outcomes in respect of the care experience of patients with dementia, from their perspective and that of their relatives/ caregiver/ significant other;
d) organisational and clinical outcomes for people with dementia in acute care.

Research Design

The proposed study will perform a mixed method, multiple case study design in the 11 participating wards within 5 Trusts. This is aimed at securing an in-depth understanding of the process of implementation and outcomes of the PIE programme in the real life setting of acute hospital wards with a substantial proportion of older people among its patients. The term „case study‟ has been used in a variety of ways (47-51). Here, it is employed to refer to a form of inquiry that is characterised by the depth and detail of information collected along a range of dimensions pertinent to the research question, within naturally occurring, bounded settings to provide a descriptive and explanatory account of a phenomenon in context.

The rationale for adopting such a design flows from the complex nature of the PIE programme and the setting in which change is introduced and implemented. The PIE programme exhibits several features of complex interventions (52): the number and difficulty of behaviours and practices required to implement and deliver it; the levels at which change is required (individual, collective and organisational); and the degree of flexibility permitted in delivering it. Further, a significant dimension of PIE implementation is time: change through successive *observation, action planning, action and review* implementation cycles mean that change is conceptualised as a process with recursive loops such that initial success (or failure) may create the conditions for further steps i.e. change is multi-directional and non-linear (53). The setting for initiating and implementing the PIE programme is the acute ward; evaluation of effectiveness requires understanding of the „how‟ and „why‟ change occurs within this specific organisational context. Focus on the ward as the setting for exploring the PIE programme is reinforced by findings from the national audit: variability between wards in the same hospital in the practice of person-centred care and lack of a common culture around person-centred care within hospitals.

Conceptual framework

The PIE programme is underpinned by a theory of change approach to implementation. Thus, there is the conception of implementation as occurring over time, through a team learning process that combines education and sensitising staff to observe taken for granted practices (19,43,54); engaging and motivating them in developing solutions by linking beliefs and values to practice improvement individually and collectively (42,55); and addressing systems and care processes that support and sustain change efforts (42).

We propose to use Normalisation Process Theory (42) (NPT) as a sensitising framework for data collection on the implementation process as it evolves over time. As a complex intervention, PIE is aimed at organisational, systems and behavioural change at ward level. From the range of theories on implementation (79), NPT offers a useful framework from its sociological perspective and utility of the broad constructs that comprise it (coherence, collective engagement, collective action and reflexive monitoring) to capture data on individual and collective action relevant to implementing, embedding and sustaining improvements in routine care. Recognising the limitations of NPT: a high level of generality and lack of attention to contextual factors, means we will also draw on insights from other research and research reviews on service improvement initiatives in health care (55,56). The key questions driving data collection on implementation then include: Does the PIE programme clarify what is distinctive about person-centred care and engage staff in articulating a shared sense of purpose around the beliefs and values that inform it (coherence)? Does the PIE programme provide a framework for action that is conceived of as a legitimate part of their routine work (cognitive participation)? Does the PIE programme facilitate staff engagement in individual and collective action and what might comprise the human and material resources required to sustain this (collective action)? Do staff individually and collectively appraise the PIE programme as worthwhile for themselves and patients (appraisal)? Additionally, given the significance of contextual factors in influencing change (44,57,58), our design (multi-site case study) and data collection methods are aimed at identifying contextual factors that may contribute to variation in outcome patterns. [See also the accompanying „response to the SDO board for PIE‟].

Sampling strategy

We have identified one acute elderly care ward and one orthopaedic ward with a substantial proportion of older people among their patient intake to participate in each of five Trusts, and an additional ward with 13 beds for people with dementia in one hospital. It is proposed that Trusts and wards be selected to provide diversity in terms of size (small, medium, large) and type of locality (metropolitan/ town with a rural hinterland) among those that express an interest in being involved in the study. Further, ward senior staff will need to demonstrate „readiness‟ to engage in a change process, specifically: expressed interest among senior acute hospital staff in participating in the research to improve person-centred care for people with dementia; and agreement of senior ward staff – specifically ward manager and practice development specialist (if relevant) – to engage in a practice improvement programme over a prolonged period; and commitment from a clinical lead with responsibility for practice development to assume responsibility for initiating and facilitating the PIE process of change over a sustained period of time (18 months).

Given the „bottom-up‟ approach to PIE implementation, it is critical that wards selected are willing to engage in the process. While this might mean that only those that are committed to change will be included in the research, the audit demonstrates that a sustained person-centred approach is atypical and the more typical picture is one of considerable distance between the aspiration and reality of person-centred care. Based on the National Dementia Audit [see also the accompanying „response to the SDO board for PIE‟], we do not envisage that selection of sites on these criteria will result in participation of only high performing wards. We will, however, employ a validated tool (Person-Centred Climate Questionnaire, 60) to screen wards expressing an interest in taking part to purposively select wards that vary in their level of person centeredness. This will ensure that selected wards are operating from a different starting point for the intervention, thereby providing a baseline against which we can evaluate „distance travelled‟ as a result of the PIE programme at 9 and 18 months. It is envisaged that if PIE is an effective programme for implementing person centred care, it could be further developed as a care improvement initiative, incorporated within a performance and outcomes framework.

Timeline for data collection

There will be three main data collection periods on each of the participating wards:
T0: 2 months immediately before PIE implementation (baseline)
T1: 2 months to commence 9 months after PIE implementation (interim)
T2: 2 months to commence 18 months after PIE implementation (follow-up)

Patients with dementia or an on-going cognition, memory or communication problem

The population of patients with dementia will need to be identified for purposes of examining clinical outcomes and purposive sampling for in-depth case study (observation/ interview). In recognition that dementia is poorly diagnosed, we will also include patients who staff consider to have an on-going problem with their memory, cognition or communication which may be undiagnosed or as a result of another condition e.g. stroke or depression, in recognition that they might benefit from the intervention. This is a pragmatic approach to patient recruitment that reflects the existing situation of poorly diagnosed dementia (34) and that the PIE programme is relevant to all these patient groups.

Assuming 26 beds per ward, 50% of patients who have dementia or cognitive impairment (which is the case in our proposed study wards), and an average length of 14 days, there should be approximately 572 patients with dementia or who meet our inclusion criteria in the study in the 11 wards/5 sites during each of the two month data collection periods (baseline, interim and follow-up) (1716 in total). During each period of data collection, a senior nurse and ward clerk on each of the participating wards will identify all current patients in the ward who either have a known diagnosis of dementia, have been screened on admission for an on-going memory problem (as part of the CQUIN) or who are otherwise considered by ward staff to fit our inclusion criteria (yes/ no). This is so that we will be able to obtain and compare individual anonymous data on clinical and organisational outcomes for our group of interest (people who may have dementia) in relation to the patient group as a whole.

The total patient group (with and without dementia) for whom we will compile a descriptive ward profile and obtain data on quantitative outcomes of interest is 3,432. The number of patients invited to participate in a case study will be up to 6 per ward during each data collection period (66), 198 over the project duration.

Methods

We will employ a multi-method, systematic approach to evaluate the PIE intervention with data collection in each of the 11 selected wards aimed at addressing each of the research questions:

1. **Ward Culture, Staff Knowledge and Understanding of Practices and Patient and Staff Profile**

   Qualitative and quantitative methods (participant observation, analysis of documents, staff questionnaires, informant interviews with senior staff, patient and staff profile) will be used to build up a picture over time of ward culture and staff awareness, understanding and practices in respect of people with dementia.

Observation of ward routines and practices: 9/12 shifts covering early morning, afternoon and night; week and weekend; to include at least 2 of ward rounds, MDT meetings and handovers.

Climate for Care Questionnaire (19) – to be completed anonymously by ward staff - a 38 item questionnaire allows for staff views to be understood in respect of: shared philosophy of care; adequacy of resources; mutual support; feeling safe; improving practice; involvement; developing skills; time pressures, and team working.

Person Centred Climate Questionnaire - for staff (60) – a 14 item questionnaire to explore the extent to which the climate (culture) of healthcare settings is perceived to be person-centred (as a screening tool for purposive sampling of wards and at subsequent time points).

Matron's Assessment of Care Questionnaire (19) – a short questionnaire to complement the above questionnaires.

Qualitative interviews with senior ward staff (e.g. manager, senior clinicians; sister, doctor, therapist, housekeeper) – to focus on understanding of, and opportunities and barriers to, providing care to people with dementia generally and person centred communication with such patients specifically.

Analysis of documents: specifically assessment and care protocols/ plans and procedures.

Ward patient profile will be developed through the collection of individual anonymous PAS data: age, sex, reason for admission, type of residence, length of in-patient stay, discharge destination, hospital mortality and 30-day re-admissions, to provide a contextual picture of the overall patient profile.

Staff profile: staffing levels, skill mix.

2. Process and Impact of PIE as a Programme to Effect Change in Staff Practices

We will use a range of data collection methods to examine the process of PIE implementation.

Organisation of 3 ward implementation workshops per Trust with staff over the 18 months PIE implementation (approximately 3, 9 and 15 months in) to examine the dynamic of change effected through the cycles of *observation, action planning, action and review*; the achievements and obstacles at each stage of the change cycle and the factors that sustain or impede individual and collective participation of staff in the process and contextual factors at both the micro level of the ward and macro hospital level that affected it.

Research observation of action planning and review meetings at the beginning and end of each PIE cycle (quarterly cycles; 6 per ward) to provide a contemporaneous account of the intervention: how activated, who was involved, problems encountered and solutions arrived at.

PIE documentation: structured tool to collect data on action plans and achievements, from completed PIE documentation.

Staff narrative accounts of the change process through interviews with a sample of ward staff (approx 5 per ward) at different levels at the end of the 18 month implementation process, providing retrospective reflection on the process and impact of change.

Events 'log': the researchers will maintain a contemporaneous „events‟ log to capture change in policies, systems and procedures outwith PIE implementation that may affect the PIE change process and outcomes.

Two cross-site workshops: upon completion of follow-up, to facilitate cross case study site comparison of experience of process and outcomes; and contextual factors influencing these.

3. Outcomes of the PIE Programme on Care Experiences of People with Dementia; and on Organisational and Clinical Outcomes

We will collect qualitative and quantitative data to examine the experience of care from the perspective of patients who may have dementia and their relatives/ caregivers/ significant others; and organisational and clinical outcomes prior to, and at 9 and 18 months following PIE programme implementation.

Observation/ conversational interviews (case studies): At each of these three time points, through general observation and in discussion with the ward manager, we will identify up to 6 patients in each ward for observation/ conversation type interview; along with their relative/ caregiver that has had most contact with them in hospital. The value of this approach is that we can locate the care experiences as described by individual patients in the context of observed communicative practices of staff with them. It is possible to engage even people with advanced dementia in evaluating their experience of acute hospital care, in ways that are both meaningful and ethical (61). We will use guidance on appropriate interview techniques for people with dementia (62-64) with which our team is fully familiar. Importantly, time will be allowed for adequate rapport building and for checking meanings and interpretations.

Organisational and clinical outcomes: We will collect data on unintended adverse events (falls and delirium incidence) for all patients admitted to the ward during the data collection periods.

Falls and delirium are the commonest unintended adverse events affecting older people admitted to hospital; dementia is a major risk factor for both; and both are amenable to prevention and therefore regarded as critical markers of care quality (80, 81). Thus, delirium incidence is associated with environmental (e.g. setting, lighting, sensory overload) and care related (e.g. fluid and nutritional intake, mobilisation, cognitive stimulation) factors, which interact with patient vulnerability factors (80) that would be affected by improved person-centred care. Specifically, median occurrence estimates for delirium are 25% (range 15-42) in general medicine and 45% (range 29-68) in trauma and orthopaedics (80). There is robust evidence that multi-component interventions that target delirium risk factors can reduce delirium by approximately a third. A previous indicative combined sample size estimate to reliably detect a 33% reduction in incident delirium (80) is 650 patients (80) (PRE DEM study group). Similarly our study sample will be sufficiently powered to detect whole group changes. Specifically power calculations using STATA version 12.1 show that for patients recruited in the follow up period only (at least 960 in each group), a drop from an average of 35% occurrence of delirium to 28% may be detected with 90% power and to 28.5% occurrence with 85% power (to 29% with 79% power).

There is evidence to suggest a modest reduction in the rate of falls with a multifaceted intervention in hospital settings (46). According to the National Patient Safety Agency (84), the most useful measure of falls is considered to be number of falls per 1000 occupied bed days, which for an average 800-bed acute hospital is 24 falls a week or over 1260 falls per annum. The estimated sample size to reliably detect a 30% reduction in falls rate is 3,000 (84).

Falls data (number of falls per patient per hospital stay) will be collected via weekly inspection of the risk register of participating wards and recorded incidents; this data is readily available and can be easily collected because hospital falls are routinely recorded in hospital trusts‟ adverse events systems as part of regular reporting and monitoring. In addition, aggregate falls incidence will be obtained for each ward as a whole from baseline to the end of the 18 months implementation phase to compare trends over time and to facilitate exploration of the data (e.g. it is possible falls rates will vary according to time of year).

Delirium identification (days spent with incident delirium) is more difficult because these data are not routinely collected. We propose to use the widely used and validated Delirium Observation Screening (DOS) scale (82). This is a 13-item scale which was developed to facilitate early recognition of delirium, according to the *Diagnostic and Statistical Manual-IV* criteria, based on nurses' observations during regular care. It comprises a single sheet completed at least once a day by nurses‟ as they attend to patients with a score of >3 indicating delirium. It takes less than one minute to complete (and is therefore not resource-intensive). We will ask for the DOS to be incorporated into ward practice in the participating sites and use this prospectively collected information to monitor rates of delirium during the study. If this is not possible, delirium will be ascertained via a case note review conducted by hospital staff (83).

Individual anonymous PAS data collected on length of in-patient stay, discharge destination, hospital mortality and 30-day re-admissions will facilitate additional examination of these organisational outcomes over time and in relation to the contextual factors and change process. Specifically, a database will be set up in each ward for an administrator/ ward clerk and/or a senior nurse to input the relevant PAS data for every patient admitted to (and discharged from) the ward during each of the two-month data collection periods. It will also be recorded for each individual whether they have dementia or an on-going cognition/ memory/ communication problem, their number of falls and number of days with incident delirium (from the DOS scale). The data will be returned to the research team with all identifiable patient details removed (the research team will only know the ward name and dates of data collection).

Analytic Strategy

Data analysis will be carried out at different levels (65,66). Analytic methods appropriate to the mode of inquiry in respect of each type of data (qualitative and quantitative) will be carried out for each individual case (ward) in the first instance and then across the dataset as a whole.

1. Specifically:
   a) With qualitative data (audio-recorded and transcribed interviews and workshop discussions; observational field notes and events log), we will employ a grounded theory analytic method (use of constant comparison and search for negative cases to develop categories and the relationships between them; and model change over time through the search for conditions and consequences that impact on the temporal flow of action and interactions and the contexts in which they occur).
   b) The quantitative data includes that on delirium, falls and data from PAS (age, sex, reason for admission, type of residence, length of in-patient stay, discharge destination, hospital mortality and 30-day re-admissions) collected at baseline, 9 and 18 months. The quantitative data will be summarised for the three time periods (T0; T1; T2), analysed and presented at two levels: **by individual wards** (n=11) to contribute to the in-depth understanding of the process of implementation and outcomes of the PIE programme in individual real-life settings with the unit of analysis being patient; and by **all wards combined** to provide a preliminary estimate of the effects of the PIE programme on patient outcomes. The unit of analysis is patient. The data will be analysed to provide descriptive statistics (for continuous variables: N, mean, SD, median, maximum and minimum) and to compare change over time at each site in patient profiles/ outcomes. A hierarchical regression model will be fitted with patients nested within wards so that adjustment may be made for measured covariates and the effect of the intervention revealed. In particular the partial and full implementation of PIE can be assessed in the different time periods.
2. For each case (ward), and using the logic model drawn from our research questions (hypothesised linkages between the PIE programme, staff practices and patient outcomes), we will develop an explanatory account of the pattern of relationships between these and the contextual factors that affect them.
3. We will then compare and contrast cases using the method of analytic induction to develop explanations that go beyond the individual case to assess how and under what circumstances the PIE intervention results in particular outcome patterns for staff, patient experiences and outcomes.
4. In recognition that the turbulence of the ward environment might affect the robustness of the findings from our study, we propose to draw on results obtained from succeeding rounds of the National Audit of Dementia (NAD). We will use national data, supplemented by local, hospital specific NAD data to "benchmark" our index wards to assess changes observed in the participating wards against national and local data, including falls and delirium incidence rates.

FLOW DIAGRAM – See Attachment

PLAN OF INVESTIGATION AND TIMETABLE - See the Attached Gantt Chart

ADDITIONAL INFORMATION

Description of the Person, Interactions and Environment (PIE) programme

PIE was developed in consultation with hospital staff and older people to be feasible for use in national audit after a one day workshop, in which the tool and process of using it is introduced, and there is discussion and experiential exercises around what constitutes person-centred care for people with dementia. PIE is presented in the form of a work-book manual, and following agreement/ preparation with the ward team, involves identifying and gaining informal consent to observe the care of up to six patients who may have dementia in a ward area. Real-time observations are conducted by two hospital staff (including one practice development nurse independent to the ward) for at least two periods of two-hours each (one early morning, one over lunch time, with flexibility to do more). Data collection involves exploring the extent to which staff are considering what is known about the individual patient as a Person to personalise their care; the quality of Interactions with staff and the impact of the immediate *modifiable* physical Environment (such as noise levels) or organisation of care (such as staffing). Each ward reflects on the findings and then identifies an area of good practice and an area which requires considerable improvements in person-centred care, together with easily achievable short-term actions for the ward and longer-term actions for the directorate and Trust.

The research-led development phase (with Research Ethics approval) enabled pilot work in seven NHS trusts (18 wards) with encouraging and positive findings. PIE was found to be simple and enjoyable for staff to use; gave rich and honest descriptions of the care experience; enabled staff to see care from the patient perspective thereby raising their awareness ("It"s like having a story unfold in front of your eyes." "You really do see"); was sensitive to what did not happen and identified contextual factors (care practices and organisational routines) that impinged on staff/patient interaction.

A distinctive feature of PIE is that it is not simply a tool to evaluate existing practice; it encompasses an implicit process for changing and sustaining practice. We have therefore developed PIE into a quality improvement intervention that addresses the widespread deficiency in person-centred communication for people with dementia that emerged as an important finding in the national audit. The PIE programme comprises the PIE observational tool and the accompanying educational and development materials linked to a process of change. This entails *observation, action planning, action and review* implementation cycles. Specifically: identifying the clinical team, preparing the clinical team to use PIE, piloting PIE, using the PIE tool to assess current communicative practices, reflecting on the findings, feeding back the findings to the ward team, developing an action plan, celebrating and disseminating improvements, reviewing progress, repeating PIE in a cyclical process. Reviewing the change processes and mechanisms that support this will result in a supported evidence-based method and manual suitable for wider dissemination to NHS Trusts. The PIE programme is unique as there are no other observation based quality improvement tools available for use by hospital ward teams with respect to people with dementia. [See also the accompanying „response to the SDO board for PIE‟].

PROJECT SUMMARY

Improved care for people with dementia admitted to acute hospitals (at least 25% of patients) is a national priority as care quality is unacceptably low with negative ill-effects being reported on general physical health, symptoms of dementia such as becoming more confused and less independent, increased length of hospital stay and admission to residential care. This also leads to increased costs. Older people and their families place high value on personalised and dignified care experienced through relationships with staff. Person-centred care is therefore an essential component of good quality acute care, especially for people with dementia, and should help to empower staff to improve patient and carer experiences and outcomes. The necessity of making changes to the culture of care delivery has been reinforced by successive government initiatives since 2001 and by Patient Association reports (67,68). It has proved challenging for ward teams to implement person-centred care given the fast pace of care delivery, pressures to meet targets and the focus on short-term medical problems. There has been some research to inform progress in this area for older people but little specifically for people with dementia.

As part of our national audit of care received by people with dementia in general hospitals (England and Wales), we developed a qualitative observational tool called „PIE‟ (to look at the „Person‟, their „Interactions‟ with staff and the immediate „Environment‟) to help hospital staff understand patients‟ experiences in real time and to develop action plans to improve person-centred practice in their wards. It was successfully piloted in seven NHS Trusts then used by ward staff with 608 patients in 43 Trusts (105 wards) for the national audit. The findings were reported in December 2011. These have helped to provide a concrete definition of what person-centred care looks like in practice for people with dementia in hospital. It was revealed that communication between staff and patients is especially critical to address not just the social and emotional needs of people with dementia (such as for orientation or reassurance) but also their ability to participate in the processes of care (such as hygiene or eating and drinking) essential to their acute care recovery. A framework for the steps that need to be taken by wards to improve communicative practices was defined, for example encouraging all staff to interact with patients at every opportunity and knowing and using information about each person to help guide interactions. Most wards are currently falling short of providing care which is person-centred more often than not with only five wards providing evidence of exemplary practice and a consistent flexible response to individuals with dementia. Although action plans for change were identified in each ward, for example changing the organisation of care delivery at meal-times to encourage patients to eat appropriately, the means by which those action plans can be implemented or the processes required to support organisational change using PIE are unknown.

The proposed research therefore intends to implement the PIE „programme‟(tool and a linked change process) as a longer-term strategy in five NHS Trusts (11 wards) over 18 months to develop person-focused communication practices and to explore how or whether this actually effects change. It is hypothesised that person-focused communicative practices will lead to improvements in person-centred care and associated health outcomes for people with dementia. Minor pre-preparatory work to further refine the PIE tool and accompanying learning and development materials will be undertaken. Research ethics and research governance approval will be sought and obtained prior to study commencement in five hospital trusts (one elderly care and one orthopaedic ward at each site and an additional ward with 13 beds for people with dementia in one hospital). Before the PIE programme is used by the ward team, quantitative (baseline) data will be collected on patient characteristics (age, sex, reason for admission, usual residence and whether they have dementia or an on-going problem with their memory, cognition or communication). Also, individuals‟ length of acute stay, common adverse complications of hospital admission (delirium and falls) and outcomes (discharge destination including new care home admissions, 30-day readmissions and mortality in hospital). Qualitative research observations will be undertaken of ward routines and the quality of patient-staff interactions, and people with dementia/ cognitive impairment and their relatives/ caregivers asked about their experiences of care. Staff perceptions of the working environment and the extent to which they feel supported to provide person-centred care will also be assessed. For practical reasons, two Trusts will participate two months prior to the other three Trusts. Therefore, baseline data will be collected during Months 6 and 7 in Trusts 1 and 2 and Months 8 and 9 in the remaining Trusts. Following implementation of the PIE programme, a follow-up study (repeat of the baseline) will be undertaken at 18 months to investigate impacts on patients and staff. Some data will be also collected half way through the intervention („interim‟) at each site. Ward team workshops will also be held at key stages to help inform an understanding of the processes of change occurring at each site. Regular updates/ progress reports will be provided to publicise the study. On-going analysis and write-up will be completed by Month 35 with national dissemination at Months 34-36. Please see the attached Gantt chart for further information. The project will have ongoing public involvement by means of representation of two co-applicants and through two reference groups (one being our longstanding arrangement with a group of local older people and one with people with dementia/ their caregivers, organised through a local memory café group).

The ethical issues were previously carefully considered during the pilot work to develop PIE and a favourable Research Ethics Committee opinion received. The approach taken in PIE ensures that patients are constantly monitored for signs of distress or discomfort caused by the observations and, if present, observations cease. The research will be co-ordinated through the Bradford NHS-based Academic Unit of Elderly Care & Rehabilitation, University of Leeds. The AUECR has a current grant income of over £8 million (MRC and NIHR) with expertise in multi-site, multi-method research designs. The applicants for this project have been working together developing PIE since 2008. The team collectively comprises national experts on dementia, frail older people, quality improvement, practice development and person-centred care and research expertise in the design and conduct of complex studies. The research will be conducted over three years. Funding of £442,979 is requested, principally to support a Project Manager and two assistants to conduct the multi-site programme of work. The outcome of the proposed study will be an evidence-based tool and manual, including training materials and implementation process, designed to enhance person-centred communication and care for people with dementia in acute hospital wards with wide applicability across the NHS.

CONTRIBUTION TO THE COLLECTIVE RESEARCH EFFORT

It is estimated that there are currently over 820,000 people with dementia in the UK, with an anticipated doubling over the next 30 years. The neuropathology of the various dementia types is now better understood but only limited progress has been made with pharmacological agents (69). Providing high quality support and personalised care, therefore, remains a cornerstone approach. Given the dominance of older people in acute care, the lack of attention in acute general hospitals to the care needs of people with dementia has major consequences in terms of poor outcomes for individuals and excess healthcare costs (more than £6m per year for an average general hospital) (16). The NICE guidelines on dementia (70) made a specific research recommendation to investigate the effects of staff training on outcomes for people with dementia. A systematic review summarising the research evidence (1986 to 2006) for best practice management of older people with dementia in acute care settings (31) indicates need for multi-faceted interventions: early detection and assessment, informed knowledge and attitudes of nursing staff, focused communication, a reduction of external (environmental) and internal stressors (unmet needs such as pain), and patient and carer involvement. Other important areas include attention to physical care as a risk factor in delirium, adequate nutrition and hydration, and training for staff, which are not currently well addressed in England and Wales (31,34). The challenges for staff to prioritise or incorporate person centred dementia-sensitive care within the acute context, with its fast pace of care delivery and pressures to meet targets or focus on a short-term medical problem, cannot be understated (19). The PIE programme, by incorporating these principles, would help to fill this gap.

Although the person-centred approach has value as a humanistic philosophy, there has been little previous evaluative work to test rigorously the concept in relation to improving outcomes of people with dementia in acute care (31,32), although Dementia Care Mapping (DCM) (39) has been tested in non-acute settings (74). Other initiatives to improve patient experiences through a cultural shift in care (e.g. 19,29,33,75-78) are not dementia-specific. PIE has built on these initiatives with a specific focus on articulating the concept of person-centred care in a ward context to address communication and environmental factors that impede recovery for those whose cognitive impairment increases vulnerability. If the change process embedded in the PIE programme can be demonstrated to effect and sustain change in routine care and improve outcomes, it can provide a generalisable mechanism for improving acute care for people with dementia.

The main output of the study will be an evidence-based tool and implementation process (PIE programme) to enhance person-centred communication and care for people with dementia in acute hospital wards. Further, the change process model has the potential for generalisability to other areas of acute ward practice. Interim outputs will inform the NHS community and related stakeholders (e.g. professional and user organisations) of progress, the process of change (which may occur in a non-linear fashion or be of different strengths) and contextual factors that facilitate/ hinder change at different time points.

Knowledge mobilisation/ exchange will occur with the emerging findings in relation to the research questions at the following time points:
Month 7: Initial awareness-raising/ publicity of the study
Month 12: Report of baseline findings and brief update about commencement of the implementation programme
Month 22: Report of interim findings
Months 34-36: National dissemination

These will employ different media messages tailored to different audiences, with opportunities provided for comments or feedback to the research team as follows:

- **Information and interim progress reports to publicise the study and emerging findings via:**
    - Electronic newsletter (6-monthly) to be widely distributed to interested parties
    - Project website to include discussion board and area to share challenges and successes
    - The Royal College of Psychiatrists‟ lists of key contacts with all NHS Acute Trusts in England and Wales, including those that participated in PIE for the national audit
    - Direct links with the Royal College of Psychiatrists‟ ongoing audit work and dissemination of PIE and associated links to the DH
    - Social networking approaches and using the royal colleges, professional organisations, patient groups and charities to include links on their sites as well as press releases
    - The on-line and interactive website of the Alzheimer‟s Society through our PPI co-applicants
    - Established networks and partnerships of the Association for Dementia Studies and the Bradford Dementia Group with care providers, commissioners and educators, for example, with regulators such as the Care Quality Commission, Bradton teaching resources and Pilgrims projects.
- **Other avenues for national dissemination:**
    - An interactive online resource (via a project website) and digital stories (which are low-cost) for hospitals to share good practice
    - Journal articles to be submitted for publication to popular and peer-reviewed research journals to reach a wide range of audiences e.g. NHS staff including clinicians and non-clinicians, managers, academic colleagues
    - Impact statements and case studies for national dissemination will be published
    - Presentations at national or international conferences to disseminate research and best practice with older people and people with dementia e.g. UKDC and the BGS annual meeting
    - For people with dementia and their carers‟, we will work with our PPI co-applicants and the Alzheimer‟s Society to develop a dissemination programme
    - We will consult with our local Older Person‟s Forum and Memory Cafe group to explore non-online methods for local dissemination (important for people who do not have skills/ access to IT) which could be recommended to the sites participating in the evaluation (this would have minimum impact on research resources). Ideas could be articles in local newsletters or giving information updates to key contacts in the hospital and community (e.g. volunteer services, council representatives).
- **Knowledge exchange at the conclusion of the programme towards extending the use of PIE.** We will work with the Royal College of Psychiatrists‟ and the Royal College of Nursing to consider:
    - Innovative networking opportunities such as set-up of a Google wiki for global access
    - Development of an e-learning resource
    - Accreditation of the PIE tool
    - Incorporating PIE into undergraduate and post graduate curricula.

APPROVAL BY ETHICS COMMITTEES

The project will require ethical approval to be obtained prior to funding being awarded. The pre-funding preparatory work will not require patient participation in research. The ethical issues were previously carefully considered during the pilot work to develop PIE and a favourable Research Ethics Committee opinion received. The approach taken in PIE ensures that patients are constantly monitored for signs of distress or discomfort caused by the observations and, if present, observations cease.

The main ethical issue is one of consent to participate in ward observations carried out for the research and patient/ caregiver interviews, especially with regard to patients who might have dementia or delirium, memory or communication problems and who may be receiving palliative care, or severely physically or mentally ill.

The researchers will seek advice from staff on whether it is appropriate to approach individual patients or their relatives/ friends for consent. The research team has considerable experience in conducting research with people with dementia as participants. The consent process will also take into account the implications of the Mental Capacity Act (2005). Relatives/ friends or nominated consultees will be involved in making a decision in the best interests of individuals if they do not have capacity to give consent. If they assent for the individual to be involved, and provided there are no behavioural indications that the individual does not wish to participate, then we believe it is ethical to include such individuals in research. However, if there are any indications during data collection that the patient is uncomfortable and/ or does not wish to participate any longer, then their consent/ assent will be withdrawn. The consent procedure in this research is seen as a process rather than a one-off event, with individuals being given information about the study on a repeated basis, and a sequence of opportunities being provided to withdraw if this is their wish.

The inclusion criteria will be inclusive of patients who have probable dementia i.e. problems with memory, cognition or communication during their hospital stay, so that they might benefit from the study. There are practical and ethical issues around diagnosis which would be incurred by only including people with a formal diagnosis. For ethical reasons, patients will be excluded if they are unconscious or close to death. Risks and burdens include the discussion or observation of negative aspects of care with patients and their relatives/ caregivers, the possible intrusion of privacy during observation, concerns about confidentiality and the potential misunderstanding of the research by the participant due to cognitive problems or having difficulty with the English language. Reassurances will be made that the method developed is designed to highlight instances which might cause distress to staff to prevent their re-occurrence and serious untoward incidences will be reported to senior ward staff on duty. Also, that the person's care will not be affected, whether they decide to take part in the research or not. Research observations will aim to be as unobtrusive as possible and if any signs of distress related to their presence are observed, the researchers will take appropriate action to minimise this. It is intended that informal unstructured conversations be held with and individually tailored to each participant, in order to enhance their contribution and minimise any potential distress. Reassurances will be made during the consent process that data collected will be treated confidentially and findings reported anonymously. Information will be presented as simply and clearly as possible to participants, with the assistance of an interpreter if necessary. Our previous experience and knowledge of using observational methods in research is informed by a person-centred approach. This suggests that the risk of discomfort or intrusion to patients during observations is minimal and the potential benefits of raising awareness and helping staff teams to improve quality of care for people with dementia great.

Consent will be sought from staff to participate in interviews and ward team implementation workshops. Following an expression of interest from their ward to participate, ward staff and other staff who visit the ward (e.g. clinical, domestic, catering) will be provided with an information leaflet about the study and what participation would entail at least 3 weeks before the meeting. They may contact the researcher beforehand with any queries. Potential staff participants will be advised in the initial information they receive that the interview/ meeting will also be recorded and transcribed. If they are still willing to participate, they will be asked to complete a consent form, including for the audio recording. Reassurances will be made in the information leaflet that there is no obligation to take part in the study. Although the hospital management will be formally supporting the research, the hospital staff workshop(s) will be limited in numbers and it is anticipated that staff should not therefore feel undue pressure to participate. Consent to complete a questionnaire will be assumed upon completion.

PUBLIC INVOLVEMENT

Plan to involve patients and/ or the public

The purpose of PPI involvement is to gain the advice and opinions of representatives of people with dementia and members of the public who have experience or an avid interest in the care received by people with dementia and their families in general hospitals. There are three proposed strands. The first is engagement of our well-informed ongoing local Older Person‟s Forum (of approximately 15 people) with whom we have a longstanding relationship and who contribute at all stages of our delirium and dementia research projects. Meetings with the group will be regularly held, including at four critical time points. The second is engagement of people with dementia and their carers‟ at key stages of the study, facilitated by our contact with the coordinator of a local memory café group, who has agreed to support the study. The third is the involvement of two Alzheimer‟s Society research network volunteers as co-applicants. Further details are as follows:

1. **Local Older People's Forum Delirium and Dementia Subgroup**
   Members of the public who are older and have an interest in, or experience of having, confusion in hospital have been accessed through our local Older Person‟s Forum (Bradford Council). This is a

group of approximately 300 vocal, well-organised, retired local people who have been consulted on several local health and social policy issues. A smaller group of approximately 15 people from the main Forum has been acting as an advisory body for our on-going delirium and dementia research since July 2007.

This sub-group have a longstanding involvement in advising this research to date. They were involved in the development of PIE for the national audit, for example advising with regard to ethical issues and the design and presentation of the tool. For this project, members of the group will be actively involved at the following critical points and additional meetings will be held as required. The time points are:

a) Baseline stage (Month 6) – advice on the data collection tools to be employed with patients and relatives/ carers for the case studies (observation and conversations/ interviews).
b) End of baseline (Month 11) – to test out the emerging understanding of ward culture and patient experiences gathered through observations and interviews.
c) During implementation of PIE (Months 17 and 22) – to discuss issues coming out and the process of implementation.
d) Towards the end of the project (Month 32) - to discuss emerging findings and dissemination.

There is minimal cost associated with running each group meeting. We may also invite someone local who has personal experience of dementia, either from the group or through the Memory Café Group, to attend research team meetings.

2. **Local memory café group involvement**
A colleague who facilitates a weekly Leeds based memory cafe group known as “Memories Group” (via a charity called „Caring Together‟), and with whom we have contact via another research project, has agreed to help facilitate the involvement of people with dementia or memory problems and their relatives/ caregivers as appropriate throughout the project. This will complement the Older Person‟s Forum by means of representing the interests of people with dementia directly. The suggestion is to hold approximately six meetings with the group who comprise 8-10 members (or individual representatives who have a particular interest in the study) throughout the PIE programme implementation phase. The intention is to explore what could be better in practice on acute wards from the perspectives of people with dementia. Then we can compare their perceptions of what could be bettered and how to initial and subsequent steps taken by the wards following their PIE observations. Feedback will be given directly to the research wards, and vice versa, thus creating an on-going dialogue between what people with dementia would want in hospital and what is being developed in practice.

In addition, at the follow-up stage of the project, it is intended that 2 workshops be held with staff from across the NHS Trusts to facilitate cross study site comparison of the experience of process and outcomes. People with dementia or memory problems will be supported to attend these (two people at each workshop, 4 in total, together with caregivers if appropriate). They will listen to the discussion and be supported to contribute, with a separate session subsequently to provide feedback to the research team.

3. **Carer representatives on the Project Advisory Team**
Two research volunteer representatives from the Alzheimer‟s Society, who gave advice on the outline submission, have agreed to be co-applicants. They have each had experience of a close relative having dementia. Together with the opportunity to provide ongoing advice throughout the project, their involvement will be:

a) As members of the project advisory group
b) If possible, attendance at a cross-sites workshop (as outlined above).

With respect to our carer representatives and their attendance at project advisory meetings, and to contributors to the cross-sites workshops, travel costs will be reimbursed for each participant and the recommended nominal sum of £100 factored into costs on each occasion.

Details of active involvement in the development of this proposal:
At the outline stage, we participated in the Alzheimer‟s Society NIHR themed call in dementia PPI one day workshop held 5 May 2011. The feedback received was constructive with a clear need being seen for the

research and helpful advice provided. Please see the attached letter of support from the Alzheimer's Society. Two of the Research Network Volunteers who advised us at outline stage agreed to be co-applicants for the project and have given well-informed and valuable suggestions, with Frank Arrojo and Matt Murray from the Alzheimer‟s Society participating in a research team meeting we held on 26 Sept. A meeting was also held with 6 members of our local Older Person‟s Forum on 27th Sept 2011. They responded very positively to the presentation of the conceptual framework developed in the PIE research to date, with this resonating with their experiences, and will fully provide us with their continued support.

PROJECT MANAGEMENT

John Young is chief investigator and will have overall responsibility for conduct and management of the study. John has been costed at 5%. However, he has additional availability due to the annual three months sabbatical from clinical work that has been agreed by Bradford Teaching Hospitals NHS Foundation Trust to extend his contribution to research. Rosemary Woolley will be project manager with day-to-day responsibility for the coordination and management of the project at all stages. She has past experience of managing an evaluation project on a day-to-day basis ("the Enriching Opportunities Programme" with Professor Dawn Brooker). Mary Godfrey will provide day-to-day senior management and supervision of the project manager and research fellow in Bradford and will lead and provide advice with the qualitative components of the project, which are substantial. Kim Manley, principal investigator at one of the research sites, will provide day-to-day senior management and support for the 0.5 FTE research fellow to be employed in East Kent. Robert West is Professor in Biostatistics at the University of Leeds and has expertise in relation to the statistical analysis of observational studies in the area of applied health research. Robert has agreed to take lead responsibility in planning and advising the quantitative analysis of the datasets for the project. Communication with co-applicants will occur during project advisory group meetings to be held on a quarterly basis. Individual travel cost for colleagues have been included in the proposal. The PIE team (except our consumer co-applicants) has a longstanding relationship and communicates regularly via face-to-face meetings, telephone and e-mail with respect to this and related research.

NETWORK COLLABORATION

We will work with DeNDRoN network and site specific CLRNs to support the development and delivery of our study. West Yorkshire CLRN has been contacted for their advice re NHS Support and Estimated Treatment Costs and they are in support of the study.

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