

## **Managing Faecal Incontinence in people with advanced dementia resident in Care Homes (FINCH study )**

### **Summary of Research**

**Background and Rationale:** Faecal incontinence (FI) is the involuntary loss of liquid or solid stool that is a social or hygienic problem. The prevalence of faecal incontinence in care homes is high. Older people with dementia with FI have a reduced quality of life and are at risk of developing further serious health problems. Faecal incontinence is not an inevitable consequence of old age or advanced dementia and its causes are multi-factorial. There is good evidence on risk factors and associations, but very few intervention studies. The effectiveness of programmes to address the known problems of faecal incontinence in care homes is contingent not only on specific bowel-focused interventions, but also on contextually situated decision making. There is therefore a need to draw on a range of evidence sources to capture this to understand how, why and in what circumstances, particular programmes to reduce FI work (or not) for people with advanced dementia in care homes.

**Aim** To explain the effectiveness of programmes that aim to improve faecal incontinence (FI) in people with advanced dementia in care homes. The objectives are:

1. Identify which (elements of the) interventions could potentially be effective, how do they work, on what range of outcomes (i.e. organisational, resource use and patient level of care) and for whom (or why don't they work)
2. Identify the barriers and facilitators to the acceptability, uptake, and implementation of interventions designed to address FI in people with advanced dementia resident in care homes
3. Establish what evidence there is on the relative feasibility and (where appropriate) cost of interventions to manage FI

**Method** Realist synthesis (Pawson et al 2004,2005) will be used to identify the theories and the mechanisms, by which the authors of studies explicitly or implicitly assume that the intervention to reduce FI works (or explains why it fails to work). A realist synthesis will identify and explain the interaction between context, mechanism and outcome, to establish which interventions, or elements of interventions, work for whom and in what circumstances. Interventions of interest include those that focus on assessment and recovery of physiological function (Norton et al 2012), medication review (Gage et al, 2010, Parsons et al 2011) equipment (Fader et al 2008) toileting regimes (Schnelle et al 2003), those that address system wide issues about access to assessment, and treatment (Davies et al 2011) as well as those that, by association, have the potential to improve bowel related care (e.g. studies on urinary incontinence, dignity, interventions to improve communication with people with advanced dementia, strength and mobility, nutrition, oral hygiene and speech and language assessment).

An iterative four stage approach is proposed that is stakeholder driven and optimises the knowledge and networks of the research team.

**Phase one.** To develop programme theories of how FI interventions work it will focus on the contextual conditions and mechanisms that influence how FI is effectively managed in care homes for people with dementia. A consultation with five key stakeholder groups (user/patient representatives, care home providers, clinicians, care home researchers and continence specialists) and a first search and mapping of the literature will identify why certain approaches to addressing FI with people with advanced dementia work (or not), in what circumstances and why. A one day workshop will review the findings and agree an explanatory model and associated candidate programme theories to guide the next stage of the review process

**Phase two** will systematically search the published and unpublished evidence to test and develop the theories identified in phase one. Initially it will target evidence relevant to the promotion of faecal

continence in long term care but inclusion criteria will be expanded in light of emerging data to ensure relevant and rigorous evidence is included. This is likely to include evidence from dementia research; care home focused interventions and practice development literature. How the programme theories are 'tested' will be made visible through the data extraction forms that will populate the evidence on Context Mechanism and Outcomes (Rycroft-Malone et al 2012). Synthesis of the data will involve the organisation of evidence tables and identification of themes that cut across the evidence tables that either support or negate certain context–mechanism-outcome configurations. A second one day workshop will review findings and resultant hypotheses that summarise the nature of the context, mechanism and outcome links, and the characteristics of the evidence underpinning them.

**Phase 3: Test and refine programme theory/ies (validation)** To facilitate the development of a final review narrative and a refined set of hypotheses. We will validate our findings and final narrative from Phase 2 by testing them, and then iteratively refining them, through interviews with a purposive sample of participants from phase 1 as to their potential, significance, and feasibility of implementation and embedding them for people with advanced dementia in the care home setting

**Phase 4: Actionable recommendations** will be developed for practice and research of what works for whom and in what context in relation to programmes to manage faecal incontinence for people with advanced dementia in care homes.

**Dissemination** To ensure maximum impact we will also draw on our national and international networks, and link with investigators of other relevant NIHR funded projects. Outputs will include a final and full research report, and linked publications, workshop and presentations to ensure that findings are accessible to as wide an audience as possible

## Protocol

### Background and rationale

In the UK, care homes are the main providers of long term care for older people. Approximately 17,500 care homes are home to about 487,000 older people, the majority women aged eighty or older (Care Quality Commission 2010). It is estimated that as many as 80% of residents may have a dementia, though this is not always documented (Gordon et al 2013).

Faecal incontinence is the involuntary loss of liquid or solid stool that is a social or hygienic problem (Norton et al 2010). The prevalence of faecal incontinence (FI) in people aged over 80 years is estimated to range from 12 to 22% (Harari 2009). In a cohort study of primary care patients, the rate of diagnosis of FI in people with dementia is four times that in a matched sample without a diagnosis of dementia (Grant et al. 2013), and dementia has been identified as an independent risk factor for FI in several epidemiological studies [Chassagne et al 1999, Nakanishi 1997, Johanson 1997].

Estimates of the prevalence of faecal incontinence and bowel related problems in people resident in UK care homes are significantly higher than the general population. Some studies have estimated that almost a third of residents are incontinent of both urine and faeces. (Rodriguez et al 2007). For nursing homes, international studies suggest a prevalence between 40-50% (Borrie et al 1992, Nelson et al 1998, Brocklehurst et al 1999, Chassagne et al 1999, Harrington et al 2005)]. The level of variation is believed to reflect as much differences in care as opposed to the individual characteristics of the older people (Harari 2009).

National and international guidelines (NICE 2007, Norton et al 2009) emphasise that all patients with FI should be assessed for treatable causes, *regardless* of their cognitive status. Treatable causes particularly relevant to care home residents with dementia are overflow from faecal impaction, and FI

from loose stools, both of which can be assessed and managed in the care home setting. For example, treating constipation has been shown to be effective in improving overflow FI, and reducing staff workload (based on soiled laundry counts) by 42% in those with effective bowel clearance (Chassagne, et al 2000). Loose stool may be due to reversible causes such as dietary intolerances, medication side-effects including laxative use [Brocklehurst 1999 Goodman et al 2009], and antibiotic-related diarrhoea (Tal 2002). Some patients with advanced dementia lack cortical control of the defecation process, tending to void formed stool following mass peristaltic movements. Prompted or scheduled toileting (preferably after meals) has been shown to reduce frequency of FI for care home residents (Ouslander 1996 Bates-Jensen 2003). Despite the extent of FI in care homes there is a paucity of data because research in continence care in care homes tends to focus on urinary incontinence (Flanagan et al 2012, Roe et al 2011, 2013).

Continence related problems in care homes are an example of where healthcare and social care needs overlap. Help with toileting is a personal care need, however, when problems are experienced this can lead to associated dermatitis, weight loss, dehydration, delirium, discomfort and sometimes hospital admissions (Morley 2009, Gray et al 2012). FI frequency is the primary outcome of interest in NICE CG 49, being strongly linked to negative impact on quality of life (Markland 2010, Perry 2002, Bharucha 2004, 2006, NICE 2007). It also affects opportunities for social interaction and stimulation and can compound the isolation already created by living with dementia (Drennan et al 2011). Dealing with faecal incontinence may also affect care home staff turnover and morale in a workforce that is already low paid (Hussein and Manthorpe 2002) with little clinical support. Management of FI can come under the remit of various health care professionals (e.g. gastroenterologists, geriatricians, GPs, nurses); this leads to care that is fragmented and uncoordinated (Wagg 2008).

In 2012 a specific care home continence audit, educational and care planning tool (based on NICE CG 49 standards) was piloted in the UK. This highlighted some of the process and organisational problems that care professionals in this setting have that can be barriers to FI programmes (RCP 2012). Ageism, lack of training, pad restrictions due to cost control and poorly integrated services were identified as likely contributors to low standards of care for FI. A review of English local continence guidelines (Drennan et al 2013) revealed a paucity of dementia specific information, which would suggest that even when specialist continence services are involved in supporting people with dementia in care homes, the resources for dementia-specific advice for residents with faecal incontinence are limited.

There is however an extensive care home and dementia specific research literature on the impact of the leadership, culture of care and care home routines on residents' health and wellbeing (Froggatt et al 2009), as well as relevant intervention research. For example, contributing factors to FI include impaired mobility, stroke, and diabetes. Care home studies on nutrition and hydration (Kenkman et al 2010), patterns of meal times (e.g. Abbott et al 2013), medication use (e.g. Barber et al 2009, Parsons et al 2011) diabetes care (e.g. Sinclair et al 2012) activities of daily living (e.g. Sackley et al 2006, 2009), all have the potential to inform implementation of FI programmes of care. This literature has also demonstrated the contextual significance of the intrinsic heterogeneity of the care home market. A 'care home' can operate with or without on-site nursing services and vary significantly in terms of ownership, size, specialism, structure, staffing and funding. In recent years providers have been amalgamating homes as part of re-provisioning, in order to harness economies of scale (Laing and Buisson 2013). The extent to which an individual's care is supported by public funding is subject to local variation, within country specific policies (Humphries 2013). In the UK access to medical care is provided in the main by primary care and the extent to which specialist nursing, therapy and medical services is available to residents and care staff is highly variable and arguably, inequitable (Glendinning et al 2001, Davies et al 2011, British Geriatrics Society 2011, Gordon et al 2013).

The underlying assumption of this proposal is that the effectiveness of programmes to address the known problems of faecal incontinence in care homes is contingent not only on specific bowel-focused interventions, but also on contextually situated decision making (Rycroft Malone 2008). Any intervention designed to address faecal incontinence in people with dementia in care homes will inevitably be multi-component, dependent on the behaviours and choices of those delivering and receiving the care, and be characterised by a context-dependent effectiveness.

The heterogeneity of settings, and the wide ranging needs of residents has led researchers investigating interventions in these settings to argue for interventions targeted to specific sub-groups rather than whole homes (Underwood et al 2013) and using case management types approaches (

Kane et al.2004 ). However, the relationship between evidence use, care experiences, quality of life and overall standards within care homes are not well understood or articulated (Tolson 2011). Professional and research evidence is also beginning to query the sustainability of interventions that have not been developed in collaboration with care home staff and in consultation (where possible) with residents and their representatives (British Geriatrics Society 2011, Goodman et al 2013). It has been reported that successful continence interventions are not sustained in USA nursing homes once research support is withdrawn (Schnelle et al 1998)

A current NIHR study has identified a range of models and theoretical assumptions that underpin care home targeted initiatives to improve residents' overall access to health care and health outcomes. These range from the use of governance structures and financial incentives to improve clinician engagement, problem specific education and training interventions delivered at the resident level of care, relationship building approaches that focus on what works well within an organisation to inform future work and interventions that improve communication, skills and staff confidence in topic specific areas of care (Goodman et al 2013).

There is a need to synthesise the different strands of research evidence to inform the development of more explanatory and theory-driven interventions that address the realities of working in and across complex, overlapping systems of care. This requires a review that can encompass:

- Evidence about the physiology of faecal incontinence in ageing populations
- Relevant evidence from studies in this population that have focused on the management of urinary incontinence
- Evidence of the relative effectiveness of different FI treatments/programmes for people with advanced dementia
- Evidence of the relative acceptability and efficacy of different types of incontinence products e.g. absorbent pads
- Evidence of the experience of living with dementia and incontinence from the perspectives of the person with dementia and their paid and unpaid carers.

It is also important to understand the ways in which public funding is deployed for continence care in care homes settings and any consequences for FI management at the individual and organisational level of care.

Realist synthesis aims to make explicit the mechanism(s) of how and why complex interventions are effective (or not) in particular settings (Pawson 2006). It is a theory driven review process that recognises that the management of faecal incontinence will always be jointly produced between the intervention as designed, the different participants, the different care home settings and how the stigmatised conditions of dementia and faecal incontinence are acknowledged (Drennan et al 2011).

Realist synthesis methodology will enable us to deconstruct the component theories of different FI related interventions and consider relevant contextual data to test our understanding of the applicability of different approaches for this population and setting.

### **Why this research is needed now**

The population with dementia is set to rise overall and evidence suggests greater numbers with advanced dementia will require residence in care home settings.

The current evidence about FI in care homes is mixed with some good evidence on risk factors and associations, but few intervention studies. The most recent Cochrane systematic reviews of the evidence base for FI have concluded that there are no randomised studies specifically in this patient group (Coggrave et al 2012, Norton et al 2012, Maeda et al 2012.). There is a need to develop explanatory models for effectiveness that can draw on different sources of evidence to increase understanding about which interventions are likely to be most useful for people with advanced dementia in care homes.

Clinically continence care for this population is ad hoc and whilst NICE (2007) guidance on FI reference the contribution of continence advisory services, provision is variable (RCP 2010). It is an area of care that lacks guidance on effective implementation of best practice, cost-effectiveness and resource use.

This research is needed to provide a theoretical framework for practice and future research work that articulates the barriers and facilitators to effective management of faecal incontinence for this population and provides a benchmark of what supports the effective management of FI for this population and setting. By providing possible explanations for the way in which interventions are thought to work and how change is achieved this realist synthesis will demonstrate how to make an intervention most useful. This in turn will inform current practice and the propositions arising from the review will inform the design of future intervention studies.

### **Aims and objectives**

This study will use a realist synthesis approach to explain the effectiveness of programmes that aim to improve faecal incontinence in people with advanced dementia in care homes and to investigate the barriers and facilitators to implementation.

The objectives are:

1. Identify which (elements of the) interventions could potentially be effective, how do they work, on what range of outcomes (i.e. organisational, resource use and patient level of care) and for whom (or why don't they work)
2. Identify the barriers and facilitators to the acceptability, uptake, and implementation of interventions designed to address faecal incontinence in people with advanced dementia resident in care homes
3. Establish what evidence there is on the relative feasibility and (where appropriate) cost of interventions to manage faecal incontinence

### **Realist review approach**

Realist synthesis is systematic, theory-driven approach designed to make sense of diverse evidence about complex interventions applied in different settings (Pawson 2006, Rycroft Malone 2008, 2012, Wong et al 2013, Hardwick et al. 2013). Realism understands causation as working through causal mechanisms that operate, or not, according to context (Westhorp 2012). Realist approaches are based on building plausible evidenced explanations of observed outcomes (Greenhalgh et al 2011). It is particularly useful when dealing with a single complex social intervention that has multiple components, operates across multiple sites, and involves multiple actors or agents (Hunter et al 2012). The underlying premise of realist review is that the observed "demi-regular patterns" of interactions between the components that make up complex interventions can be explained by mid-range theories. The iterative process of the review tests those theories that are thought to work against the observations reported in each intervention included in the review (Shepherd et al 2009).

Realist synthesis will be used to identify programme theories and the mechanisms, by which the authors of studies explicitly or implicitly assume that the intervention works (or explains why it fails to work). These mechanisms are the underlying, often implicit, processes or structures, for example the presence of specialist expertise or the use of assessment tools that generate or lead to particular FI related outcomes. Thus, the goal is to identify and explain the interaction between context, mechanism and outcome, to establish which interventions, or elements of interventions, work for whom and in what circumstances.

Realist synthesis takes account of a broad evidence base as well as the experiential and clinical knowledge that relates to the physiology and management of FI in older people and specifically older people with advanced dementia living in long term care. It will also account for the heterogeneity of the care home provision in the UK e.g. that there are care homes with and without on-site health professionals.

Interventions of interest include those that focus on assessment and recovery of physiological function (Norton et al 2012), medication review (Gage et al, 2008, Parsons et al 2011) toileting

regimes (Schnelle et al 2003), those that address system wide issues about access to assessment and treatment (Goodman et al 2013 ) as well as those that, by association, have the potential to improve bowel related care (for example studies on dignity, interventions to improve communication with people with advanced dementia, strength and mobility, nutrition, oral hygiene and speech and language assessment).

The goal of the realist synthesis recommendations will be to specify the situations in which a complex intervention (i.e. a faecal incontinence management programme), modified or able to take account of certain contingencies, can achieve certain outcomes (e.g. cure or reduction of episodes of faecal incontinence or containment/management of social continence, appropriate use of medication, reduce resident distress, increase staff knowledge, improve quality of life, reduce FI-related pressure sores, reduce FI-related hospitalisations).

## Methods

An iterative four stage approach is proposed based on the stages set out by Pawson et al (2004) and captured in the RAMESES publication standards, which optimises the knowledge and networks of the research team and is stakeholder driven. The assumption is that a review on programmes to manage faecal incontinence has to consider complementary evidence on the effectiveness (and learning from) interventions to improve continence in care homes as well as studies that rely on health care professionals and care home staff working together to improve the health care of residents with dementia. For example, it is likely that it will be informed by theoretical work on:

- The physiological and clinical causes/associations of faecal and consequent morbidity (e.g. pressure sores, infection) in the oldest old (Norton et al 2012)
- Theories of interprofessional learning and practice development in long term settings and how change in individual practice is achieved and sustained with a differentially qualified workforce (McCormack et al 2007, Reeves et al 2012)
- Provision of person centred/relationship centred care for people with advanced dementia (Hughes et al 2008)
- Implementation theory on organisational and structural factors affecting integrated working between health and social care and the implementation of learning and practice development in long term care settings (Kodner and Spreewenbergh 2002, Grol and Grimshaw 2003, Kitson et al 2008,)

## Phase one: Defining the scope of the review: concept mining and theory development

Phase one will develop programme theories or hypotheses about why FI management programmes for people with advanced dementia living in care homes work or do not work. It will provide a provisional account of the impact of interventions by linking key areas of knowledge that inform how interventions are developed for this particular population.

A preliminary review will be undertaken of a selection of key literature (e.g. evaluations of relevant FI programmes, studies included in reviews) identified by the project team and through key word searches and discussions with stakeholder groups. Stakeholders will be invited to contribute on why they think certain approaches to addressing FI with people with advanced dementia work, in what circumstances and why. Five key groups have been identified although other expert groups may be identified, as part of the scoping process.

- Providers of care : Care home managers from the Enabling Research in Care home network ENRICH and Care home managers that are part of the My Home Life network (up to 4 focus groups purposively selected to reflect range of care home provision and workforce involved in providing care),
- Recipients of care: User representatives through the resident and relatives representatives, carer representatives and continence charities

- Academics and practice educators/developers: A meeting of the National Care Home Research and Development Forum (1 meeting)
- Clinicians with a special interest in FI : RCP group and Special interest groups on long term care and bladder and bowel conditions) of the British Geriatrics Society (1 meeting)
- Continence specialists, commissioners and providers of continence services: A focus group of representatives from the Association for Continence Advice, RCN continence Forum, and the Bladder and Bowel Foundation and commissioners of continence related resources for care homes ( e.g. equipment and training )

This will be followed by a one day workshop where the research team will begin to identify common concepts and map and prioritise the theory identified from the searches and consultation.

This process will also be informed by the complementary programmes of research, review work and clinical experience of the team (i.e. research on interventions to promote faecal continence (CN,DH), continence research in long term care settings (BR,JRM,CG,MF,DH), delivery of continence services to people with dementia and dementia sensitive care (DH,RH,VMD,JRM,FB CN) commissioning and service provision to people with dementia (FB VMD CG),continence aids and equipment (MF,VMD), practice development in care home settings (CG,JRM,BR), NICE & international guidelines and professional guidelines for continence care for people with dementia (CN,DH,VMD) and interventions to promote integrated working between health care and care homes (CG).

To ensure transparency of approach and an audit trail, we will transcribe recordings of focus group discussion and maintain structured field notes on suggestions and decision making processes about which sources of evidence were linked to which strands of theoretical development (Hardwick et al 2013).

This stage will result in a theoretical/conceptual framework and associated candidate programme theories and related contexts that will inform the remainder of the review process.

### **Phase two: Retrieval, review and synthesis**

First, we will target evidence relevant to the promotion of faecal continence in long term care. This will include interventions that address the knowledge and skills required to promote effective bowel care, specific interventions to treat faecal incontinence and related problems of constipation, diarrhoea and what works for urinary incontinence in both generalist and specialist settings. Realist synthesis enables the testing of the relevance and rigour of emerging findings from one body of literature to another. In line with the iterative nature of realist synthesis methodology (Pawson et al 2004) the inclusion criteria will be refined in light of emerging data and the theoretical development in phase one. The review is however likely to include evidence sources that cover the following:

- People with advanced dementia that have persistent FI and are resident in a care home/long term care. For the purposes of this review FI is defined as “leakage of solid or liquid stool which is a social or hygienic problem”
- Studies of any intervention designed to reduce or promote recovery from FI and or those that offer opportunities for transferable learning. Interventions may have single or multiple components, and could be delivered to individuals identified with FI or to residents identified at risk of developing FI or staff and visiting health care professionals
- Studies that provide evidence on barriers and facilitators to the implementation and uptake of interventions in care homes generally (not confined to continence), that help with understanding of programme theories and logic, or that provide evidence on underlying theories that inform the particular approach and outcomes of interest.

Research with older people with dementia and or FI living at home and or being treated in hospital will also be included and tested for the transferability of findings.

The review process will involve screening for relevance to the programme theory/ies and data extraction forms will be developed to enable us to populate the evidence on Context Mechanism and Outcomes. Outcomes will be established by the project team in an iterative process, and informed by emerging context and mechanism relationships, but are likely to include the following: the reduction and successful containment of faecal incontinence, skin health, medication and resource use, staff

knowledge, care delivery processes, and measures of older people's quality of care and life, and experience.

The evidence base to be reviewed and synthesised will be broad and eclectic (Pawson, 2006). A diversity of evidence provides an opportunity for richer mining and greater explanation. Therefore we will include studies of any design including randomised controlled trials, controlled studies, effectiveness studies, uncontrolled studies interrupted time series studies (ITS), cost effectiveness studies, process evaluations, surveys and qualitative studies of participants' views and experiences of interventions. We will also include unpublished and grey literature, policy documents and information about locally implemented continence programmes in the UK for example, that has been reported in specialist conferences (e.g. Dementia Congress, Care Home Congress) and/ or has been reported as successful, or innovative and promising, that could provide a model for future practice or merit future evaluation. Potential sources of information that will be relevant to answering the question and aims of this review are likely to include intervention studies in care homes with people with and without advanced dementia, (e.g. end of life care, urinary incontinence) as well as transferable lessons from continence studies completed in community and hospital settings. Relevant evidence will also exist in unpublished form, e.g. care pathways, care home policy documents and service based evaluations of new assessment methods or piloting of continence products. We will therefore seek to maximise opportunities for identifying this literature, through our consultations with different groups in phase one and through our project steering committee.

Our search will initially be limited from 1990 -2014 but will include seminal papers from earlier such as the work of Tobin and Brocklehurst (1986) and key international papers and those identified through lateral searches. The time limit is for several reasons. Health care research in care homes is a relatively recent phenomenon. Gordon et al (2012) identified that of 292 RCTs of interventions specifically in care homes between 1974 and 2009, half were published since 2003. Dementia research has been significantly influenced by the work of Kitwood, whose seminal work was first published in 1990 (Kitwood 1990). Furthermore, the organisation and funding of care homes was radically altered in 1993 by the implementation of the 1990 National Health Service and Care in the Community Act. This led to progressive changes in the overall size, ownership and structure of the sector. The increased emphasis on domiciliary care has also meant that the level of dependency and frailty of older people now admitted to long- term care has increased (Andrews and Phillips 2002).

We will search for published and unpublished literature. The project team will be involved in producing a list of relevant search terms to use in the following electronic databases:

- Pubmed
- CINAHL (Cumulative Index to Nursing & Allied Health Literature),
- The Cochrane Library including the Cochrane Database of Systematic Reviews, DARE (Database of Abstracts of Reviews of Effects), the HTA Database, NHS EED (NHS Economic Evaluation Database)
- Scopus
- SocAbs (Sociological Abstracts),
- ASSIA (Applied Social Sciences Abstract & Indexes)
- BiblioMap (The EPPI-Centre register of health promotion and public health research),
- Sirius, OpenGrey, Social Care Online, the National Research Register Archive, the National Institute of Health Research portfolio database Google and Google Scholar

Previous dementia reviews undertaken by members of the project team (Bunn et al 2012, Trivedi et al 2012, Goodman et al 2013) have highlighted the importance of lateral searching for identifying studies for dementia related reviews. Therefore, in addition to the above electronic database searches we will undertake the following lateral searches:

- Checking of reference lists from primary studies and relevant systematic reviews (snowballing) (Dixon Woods 2006)
- Citation searches using the 'Cited by' option on WoS, Google Scholar and Scopus, and the 'Related articles' option on PubMed and WoS ('Lateral Searching') (Greenhalgh 2005)
- Contact with experts and those with an interest in dementia, care homes and FI to uncover grey literature (e.g. DeNDRoN, National Library for Health Later Life Specialist Library, Alzheimer's society and For Dementia, RCP, RCN, Queens Nursing Institute)



- Contact with disease specific charities and user groups, residents and relatives associations
- Internet searches for grey literature and searches for continence related evaluations or intervention research which makes specific reference to faecal incontinence and or people with advanced dementia, national inspection and regulation quality reports by regulator (Care Quality Commission and predecessors)

Management of references: Search results from electronic databases will be imported to bibliographic reference management software and, where possible, duplicates deleted (Endnote). Documents from other sources will be manually recorded in the same Endnote Library. Two reviewers will independently screen titles and abstracts to identify potentially relevant documents, which will be retrieved and assessed according to the inclusion criteria below. Disagreements will be resolved by discussion.

At this initial stage, we have identified three sets of search terms. One set is focused on faecal incontinence; this set was constructed from definitions used in past studies identified during our initial scoping work and on previous related systematic reviews (CN, DH, BR). The second set of search terms is focused on care home specific interventions developed from two reviews: on health care interventions in care homes and a current realist review on models of health care delivery to care homes (CG). The third set from systematic reviews on continence interventions for people with dementia (VMD). Search terms will be revised as the review progresses and further search terms developed as the review develops.

We are confident that following on from phase one and two we will develop a comprehensive search strategy that will enable us to identify how different interventions work, their relative feasibility, the necessary conditions and likely costs. It will also enable us to capture the barriers and facilitators to the acceptability, uptake, and implementation of interventions for this population and setting.

## **Review**

The key test is the relevance and rigour of the evidence (Pawson 2006, Wong et al 2013). The guiding principle for the review is that the quality of the evidence will be judged will be on its contribution to the building and testing of relevant theory. There may be evidence that may have limited transferability to the NHS. For example, research in the Netherlands is predicated on the assumption that there will be an on-site medical director for care homes, or USA with minimum data sets, this research will not be excluded but interpreted accordingly.

There are mixed views about the use of critical appraisal tools in realist synthesis. In addition to tests of rigour built in to the bespoke data extraction tool, if appropriate and only if it aids the process, we will use critical appraisal tools appropriate to the study design. For example checklists to assess the risk of bias in controlled studies (Higgins et al 2011) and in qualitative studies (Spencer et al., 2003). Four of the research team are Cochrane editors (FB,CN,BR,MF) and all have been co-authors on published systematic, integrated and narrative reviews. We are confident that included evidence will be credible.

## **Data extraction**

The programme theories being 'tested' through the review are made visible through the data extraction forms (Rycroft-Malone et al 2012). A bespoke set of data extraction forms will be developed based on the content of the programme theory, which thereby provides a template to interrogate the theories. If the evidence meets the test of relevance (described above), data will be extracted using the form and then checked by a second member of the team. Quality assessment will be undertaken by two reviewers independently with any discrepancies resolved by discussion with other members of the project team. Where possible, the checking will be done by the team member that has the most relevant expertise (e.g. technical interventions to treat faecal incontinence, impact of care home culture, uptake of innovation etc.).

## **Synthesis**

The analytical task is in synthesising, across the extracted information the relationships between mechanisms (e.g. underlying processes, structures, and entities), contexts (e.g. conditions, types of setting, organisational configurations) and outcomes (i.e. intended and unintended consequences and impact). Rycroft-Malone et al (2012) have developed an approach to synthesis, incorporating the work of Pawson (2006) and principles of realist enquiry that includes:

1. Organisation of extracted information into evidence tables representing the different bodies of literature (e.g. health, long term care, faecal incontinence, bowel care advanced dementia)
2. Theming across the evidence tables in relation to emerging patterns (demi-regularities in realist literature) amongst context, mechanism, and outcomes (C-M-Os), seeking confirming and disconfirming evidence.
3. Linking these demi-regularities (patterns) to develop hypotheses.

Data synthesis will involve individual reflection and team discussion and will

- Question the integrity of each theory
- Adjudicate between competing theories
- Consider the same theory in different settings
- Compare the stated theory with actual practice.

Coded data from the studies will then be used to confirm, refute or refine the candidate theories. Where theories fail to explain the data, alternative theories will be sought.

Once the preliminary mapping of the evidence into tables is complete we will hold a second one day workshop with the research team. This day will be carefully structured to discuss in depth the findings and specifically develop and confirm the resultant hypotheses. These will act as synthesised statements of findings around which a narrative can be developed summarising the nature of the context, mechanism and outcome links, and the characteristics of the evidence underpinning them.

The synthesis process will reflect RAMESES publishing standards for realist reviews (RAMESES [www.biomedcentral.com/1741-7015/11/21](http://www.biomedcentral.com/1741-7015/11/21)). The transparency of a realist review synthesis is reliant on careful documentation of the reasoning processes, how they are grounded in the evidence and justification of inferential shifts through engagement with different evidence sources (Hardwick et al 2013). This aspect of the review process is resource intensive and reliant on discussion and deliberation, across and with particular members of the research team.

#### **Outputs from Phase 2:**

- A comprehensive evidence base related to on programmes designed to reduce and manage faecal incontinence in people with advanced dementia in long term care
- A set of hypotheses supported by relevant evidence to be refined in Phase 3.

#### **Phase 3: Test and refine programme theory/ies (validation)**

To enhance the trustworthiness of the resultant hypotheses and develop a final review narrative that addresses what is necessary for the effective implementation of programmes to manage FI in care homes, we will review the hypotheses and supporting evidence through interviews with two groups. These are representatives from the stakeholder groups identified in phase one and the project steering group. Stakeholder participants will be purposively sampled to obtain different perspectives relevant to the review question. It will include continence specialists, service delivery managers, regulators, academics and educators experienced in working with care homes, commissioners, and care home staff, primary care staff and PPI members (to include resident and carer groups and people with experience of FI).

An interview schedule based on the findings that have emerged from the synthesis process will focus on stakeholders' views on the resonance and significance of the mechanism-context-outcome threads both from a practice and from a service user perspective.

#### **Outputs from Phase 3:**

- A refined set of hypotheses with accompanying evidence-based narrative.

#### **Phase 4: Actionable recommendations**

We will work with the Project Advisory Group and commissioners e.g. CCG representative and care home executives to develop a set of actionable recommendations and the development of an evidence informed framework of what works for whom and in what context in relation to programmes to manage faecal incontinence for people with advanced dementia in care homes. This will be achieved through consensus meeting in London with online link to care home providers. This technique was piloted in a previous study (Goodman et al 2012) and provided care home staff with the opportunity to participate in an event that they otherwise would not have been able to attend. Using our synthesis findings, we will recommend a series of improvements and practices.

These may address the following issues:

- The synergy between particular interventions and the feasibility of their implementation in care homes
- Developing and targeting different interventions with multiple impacts and outcomes for older people with dementia, NHS and care home staff, their respective organisations and policy.
- The potential of different modes of delivery

**Deliverables from Phase 4:**

- A report of the review including relevant and actionable findings.
- Preparation of a paper for open access publication.

**DISSEMINATION AND OUTPUTS**

To ensure maximum impact we will also draw on our national and international networks, and link with investigators of other relevant NIHR funded projects. The stakeholder engagement in the research process will increase the potential of this research to be relevant and potentially usable. Stakeholders will include practitioners, managers, patients and the public, researchers and policy makers.

**Outputs will include:**

A research report, illustrated with practical examples / case studies to make findings relevant to care homes, commissioners of and providers of continence services to care homes.

Recommendations for skills development for NHS *and* care home workforce for older people with advanced dementia in care homes that experience faecal incontinence

- An executive summary of the final report, suitable for use as a separate report for briefing NHS managers, commissioners and care home managers
- A lay summary of the final report, suitable for use as a separate report
- Benchmarking or quality assurance framework for interventions
- Open access publications: 1) a review protocol (also registered on Prospero) 2) a findings paper that suggests an implementation plan for the support of people with FI in care homes and
- Conference presentation at an UK and an international national conference
- In a previous NIHR study we used online media with an older actor to present the findings of the study on the experience of being a resident in a care home. This was well received, particularly by care home staff. We propose to build on this and develop a podcast uploaded to Youtube of the main findings, including a discussion with stakeholders about the recommendations.

Through this review we will answer questions that have practical relevance to service delivery and decision makers, we will:

- 1) Provide a clear description of the interventions that have been used and evaluated for improving the treatment and management of FI in long term care settings. This will include how they work in practice and their intended and unintended outcomes. It will enable clinicians and policy makers to have an understanding of the range of strategies available, and the core assumptions about how they work.
- 2) Provide a clear explanation of the contextual influences that facilitate or inhibit good faecal/bowel continence care for people with advanced dementia with a linked explanation for care home providers, care home staff and visiting clinicians such as GPs and Continence Advisors, commissioners and policy makers of the kind of issues that they need to address.
- 3) Develop an evidence informed framework of what works for whom and in what context. This could be used by commissioners, educators and those involved in practice development in care homes.
- 4) Inform future themed calls from HTA to address this issue

**Plan of investigation and timetable**

Months -3-0

Appointment of Research Fellow and identification recruitment the of Project advisory group and stakeholder groups

Months 1- 5	Phase 1: stakeholder groups, literature searches, and workshop. Project advisory meeting
Months 4-11	Phase 2 Searches, data extraction and synthesis, workshop. Appointment of part time Research Assistant
Months 11-13	Phase 3 Stakeholder consultation and workshop
Months 13-16	Phase 4 Project advisory group meeting Final report and dissemination

In addition to the three day workshops the research team will meet every eight weeks, at least three meetings will be face to face in London and the remaining will be via teleconference and WebEX to oversee the project. Individual members will also be available for consultation by email between meetings. Access to a shared portal managed through University of Hertfordshire (UH) data management services will mean that all members of the team will be able to access included evidence and tables and contribute to the review process. This is a team that previously worked together in different groupings on a range of systematic reviews and studies specific to continence and or long term care and dementia.

The review will be overseen by an advisory group comprising experts and key stakeholders in the field with a range of experience as users of health care and care home services, in realist synthesis methodology, gastrointestinal medicine, and social gerontology and continence services for people with dementia and service users

This group will be central in ensuring that the questions addressed by the review are those of importance to decision-makers and the commissioners of the review. From existing contacts and current studies we are confident it will include representatives from the DeNDRoN, Social Care British Geriatrics Society, Dementia UK, English Community Care Association, UH public involvement in research group, My Home Life and Commissioner and managers of continence services Bladder and Bowel Foundation and the RCN Forum, as well at least three public involvement members with relevant personal experience. It is likely that sub-groups of expertise will be involved at different stages , for example, clinical, methodological, care home specific. patient and public experience.

### **Patient and Public Involvement (PPI)**

The initial idea and first draft of the proposal was circulated and discussed with members of the Public Involvement Group at the University of Hertfordshire. Members have worked with CG before in care home projects ( Goodman et al 2012). Patient and Public involvement (PPI) will be achieved in two ways. Through the engagement with user and patient representative groups at stage one and three of the review, and through PPI membership of the project advisory group There will be a minimum of three members of the project advisory group that through personal experience are qualified to comment on FI and or caring for someone with dementia and or care homes. Through previous work members of the research team have worked with user representative groups (DeNDRoN PPI group, Patients Association Age UK, Bladder and Bowel foundation, Alzheimer's Society) through these links we will identify individuals that could be interested in taking part.

Direct contact between the research team and residents with advanced dementia or their representatives is problematic. It will be possible to have on-going discussion with care home residents and staff through links with care homes. The involvement of Victoria Elliot the Orders of St John Care trust (OSJCT) care home group, and Professor Julianne Meyer Executive Director of *My Home Life programme* will enable us to secure comment and feedback from residents and family members.

### **Justification of resource requested.**

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