Title: Optimal NHS service delivery to care homes: a realist evaluation of the features or mechanisms that support effective working for the continuing care of older people in residential settings

AIMS AND OBJECTIVES
The aim of this study is to identify ways in which the delivery of existing NHS services to care homes may be optimized for the ongoing benefit of residents, relatives and staff and the best use of NHS resources. Our primary objective is to carry out a realist evaluation (Pawson and Tilley 1997, Pawson 2006, 2011) which will address the following research questions:

1. What is the range of health service delivery models designed to maintain care home residents outside of hospital?
2. What features (in realist evaluation terms: mechanisms) of these delivery models are the ‘active ingredients’ associated with positive outcomes for care home residents? (Models may include general medical services (GMS), linked community services, outreach clinics, community matrons, specialist nurses or care home support teams, pharmacist-led services, designated NHS hospital beds and enhanced payment schemes for GPs.)
3. How are these features/mechanisms associated with key outcomes, including medication use, use of out-of-hours services, resident and carer satisfaction, unplanned hospital admissions (including A&E) and length of hospital stay?
4. How are these features/mechanisms associated with costs to the NHS and from a societal perspective?
5. What configuration of these features/mechanisms would be recommended to promote continuity of care for older people resident in care homes at reasonable cost?

Research Design
A realist evaluation is proposed, using mixed methods of data collection, to establish what features or mechanisms of NHS working with care homes are associated with positive outcomes for residents and the health service.

Need
In England, most long term care for older people is provided by the independent sector. There is a need for more flexible and responsive models of service delivery and resource management that can address projected increased demand for residential and nursing home care (Laing and Buisson 2010) and anticipated funding constraints. Health care services will increasingly need to be able to work with, as well as for, care homes. To do this it is important to understand how different models of primary care access appropriate clinical support to sustain care home residents in the community.

The level and quality of care provided in homes is often tacit, care agreements between homes and the NHS are very variable. Thus services defined as health: behavioural management, monitoring the effects of therapies, doing routine dressings are often conducted by social care staff - but not always. The costs that fall to the NHS depend in each case on the extent of the responsibilities assumed by the home. Understanding the mechanisms by which the skills present in care homes can be most effectively harnessed and used by health and social care providers requires a better understanding of how these arrangements evolve and take place. This knowledge has the potential to develop a consensus between the NHS and care home providers and make explicit what NHS and care home staff recognise are "appropriate" demands on the NHS, and in the long term, reduce needs for costly interventions, including unplanned hospital admissions.

There is a need to improve within the new structures of commissioning and care, how NHS organisations (which commission and provide health services) and local authorities (with responsibilities for adult protection and contracting with care homes) work together at strategic and service levels of delivery to promote effective joint decision making and review of health care provision for care home residents. There is evidence of wide variation in the consumption of secondary health care by care home residents. Effective working between the health and residential care sectors is not only fundamental to residents’ quality of life; it influences the rate of acute hospital admissions and length of stay. But models of service delivery to care homes are many and ill-defined. This study will drill down into the models to isolate those features or mechanisms that are believed to provide conditions for effective working between
primary/community health and residential care. These will be described and operationalised in phase one and in phase two their impact, individually and in combination, on outcomes and costs will be considered

Background
In England, long term continuing care for older people is principally provided by independently owned care homes. The average resident is female, over 85 years old, and in the last years of their life. The majority of care home residents have dementia, are in receipt of seven or more medications and a significant proportion live with depression, mobility problems and pain (Goodman and Davies 2011a; British Geriatrics Society report, 2011; Gordon et al, 2011). Residents rely on primary health care services for medical support and access to nursing, specialist services and secondary health care.

Care home residents have erratic and inequitable access to NHS services, particularly those that offer specialist expertise in dementia, rehabilitation and end of life care (Jacobs et al 2001; Glendinning et al 2002; Goodman et al 2003, 2005; Alzheimer’s Society 2007; Steves et al, 2009). How problems and services are defined by the health service does not always reflect how older people and care home staff define their health needs and the types of health care they would like (Goodman et al 2012). Szczepura et al (2008), summarized the evidence on improving care in care homes with no on site nursing, and concluded that medical care could be improved by making it more proactive and preventative. They suggested that primary care should work on a more strategic basis with care homes to achieve these goals. There is a care home-specific evidence base, for example in end of life care and in medication management, to suggest that targeted support by health care services can improve outcomes for older people in care homes. However, even where the evidence-base is robust, there is uncertainty about how to sustain effective patterns of working between health care services and care homes as independent providers of care for the oldest old.

The care home market is diverse. Care homes vary in size, ownership, funding sources, focus, organisational culture and presence or absence of nursing on site. Across the NHS there are numerous approaches to health care provision for this sector including: general medical services (GMS) provided by local GP practices, linked community services, outreach clinics, care home specialist nurses or support teams, pharmacist-led services, designated NHS hospital beds and enhanced payment schemes for GPs (Hayes and Martin 2004, Donald et al 2008; ECCA 2008; JRF 2008; Sczcepura 2008; Lawrence and Bannerjee 2010; Gladman 2010; Gage 2011; Thomsell 2011). Whilst there is a good understanding of many of the barriers and facilitators affecting how health care services work with care homes. The recurrent issue is how to embed and sustain productive patterns of working between health care services and providers of care for 376,250 over 65 year olds living in 10,331 care homes which vary in size, ownership, funding sources, focus, organisational culture and presence or absence of on-site nursing. (Goodman and Davies 2011, Davies et al 2011).

The 2010 CQC survey (Carter 2011) of Primary Care Trusts found that current patterns of NHS service delivery are disparate, lacking a coherent rationale or frameworks that could support review or audit of quality or of cost-effectiveness. At the time of this survey 40% of Primary Care Trusts in England were using Local Enhanced Service payment to incentivise GP practices to provide services to care homes. However, the survey could not establish how many care homes benefited from this extra investment or in what ways. For example, the same payments could have been used to develop and expand work in care homes or address a gap in GP provision. The survey found no evidence of governance or outcome targets that were care home specific.

The British Geriatrics Society (BGS) report on the quality of health care support for older people in care homes concluded from a review of evidence and stakeholder consultation that there was a need to clarify NHS obligations to care home residents (BGS, 2011). It argued for explicit service specifications to be agreed between local commissioners and providers linked to quality standards based on patient experience and appropriate clinical outcomes. The report however, was unable to specify how these goals might be achieved.

This proposal and research collaboration draws on the applicants’ direct experience of recent research, reviews of practice and care home-based initiatives to improve the quality of care for older people and staff development. Specifically, it is informed by:
• Findings of four NIHR-funded care home based projects that team members have recently completed in care homes with and without nursing provision: EPOCH (CG, SI, HG), APPROACH (CG, SD, CV, SI, HG) or are nearing completion MCOP (AG, JS, JG) Evidem Eol (CG, SI).

• The British Geriatrics Society review and policy recommendations on health service working with care homes (FM, CB, JM, JRG CG)

• Secondary data analysis of the Care Quality Commission national survey of NHS provision to care homes (FM, CG)

• Two reviews for NIHR SSCR on undertaking research in care homes (CG, JM)

• My Home Life (www.myhomelife.org.uk), a UK-wide initiative that promotes quality of life of those who are living, dying, visiting and working in care homes for older people. is MHL is led by Age UK in partnership with City University, the Joseph Rowntree Foundation and Dementia UK and works closely with the Relatives and Residents’ Association and all the national care home provider representative organisations¹ and their individual members across the UK to improve practice in care homes (JM CB).

• SI work on appropriate and inappropriate hospital admissions and EU study on end of life for people with dementia :PaCT

• The SHELTER study an EU study that BUPA collaborated with and includes UK specific data for 400 residents in 9 care homes


For instance, we know that services at the interface between care homes and the NHS, despite using similar names (e.g. care home specialist teams/nurses, Local Enhanced Service schemes, frameworks for practice development, NHS/LA funded intermediate care/respite re-enablement beds) often have differing goals and funding sources, and operate in very different ways. While most regard integrated working as a vital objective, few interventions to improve health care delivery have been developed in collaboration with care home staff and/or taken account of the views of residents and their families. Primary care services are delivered from a distance, reliant on how care home staff interprets residents’ health status. We also know that care homes engage differentially with healthcare services and, where there are high users of services that often this arises from a small group of residents within the home. We need to consider service delivery for care homes recognizing that there may be a small number of randomly distributed very high service users

There is an inherent tension when NHS services favour models of care that focus on diagnosis, treatment and episodic involvement, whilst care home providers prioritize ongoing support and relationships that foster continuous review of care. Our research suggests this tension can be negotiated through the care home manager’s leadership, the quality of the working relationship between NHS practitioners and senior staff, and a focus on specific issues of mutual interest with supporting protocols and guidance – the Gold Standards’ Framework for End of Life Care being one exemplar. Initiatives that support co-design approaches and relational styles of working and enable shared goal setting and review have also shown promising results. Closer working between staff in the NHS and care homes does not appear to result automatically from financial incentives or the creation of NHS/LA funded beds. In fact, the relationship between effective integrated working and the models of service delivery, which might be expected to facilitate them, remain unclear.

Based on this work, the heterogeneity of care home markets and their residents, the ongoing organisational flux within the NHS and the range of context sensitive variables that shape how services are provided, we infer that it is unlikely that a single model of health service delivery can promote effective working for all care homes. Rather there will be key features or explanatory mechanisms, already manifest within multiple models and potentially applicable across multiple models in the future that will influence the delivery of optimal care. As Pawson (2011) has noted much that is

¹ National Care Forum, English Community Care Association, Registered Nursing Home Association, National Care Association in England; Care Forum Wales; Scottish Care; and Independent Health and Care Providers in Northern Ireland
effective in health care delivery is, submerged, routine and taken-for-granted, therefore the way forward is to find out what it is that makes for good practice.

We propose to identify, map, and test the features or explanatory mechanisms of existing approaches in relation to 5 key outcomes: residents’ medication use, use of out of hours’ services, hospital admissions (including use of Accident and Emergency) and length of hospital stay, costs and user satisfaction.

**Design**

There are two phases to this realist evaluation:

**Phase one:** addresses questions 1 & 2

1. What is the range of health service delivery models designed to maintain care home residents outside of hospital?

2. What features (i.e.: mechanisms) of these delivery models are the ‘active ingredients’ associated with positive outcomes for care home residents? (Models may include general medical services (GMS), linked community services, outreach clinics, community matrons, specialist nurses or care home support teams, pharmacist-led services, designated NHS hospital beds and enhanced payment schemes for GPs.)

It will

- Provide a comprehensive overview of NHS service provision, provided to care homes
- Synthesise empirical, professional and industry definitions of effectiveness to establish a consensus on the mechanisms, organisational contexts likely to achieve outcomes associated with effective health care
- Identify and operationalise features or mechanisms of service delivery and organisational contexts believed to inform phase two.

**Phase two** addresses research questions 3-5

3. How are these features/mechanisms associated with key outcomes, including medication use, use of out-of-hours services, resident and carer satisfaction, unplanned hospital admissions (including A&E) and length of hospital stay?

4. How are these features/mechanisms associated with costs to the NHS and from a societal perspective?

5. What configuration of these features/mechanisms would be recommended to promote continuity of care for older people resident in care homes at reasonable cost?

The use of longitudinal research, using a case study design, will enable us to understand the impact of key features or mechanisms for service users and the context in which impact is achieved (or not) over time. The design adopted will support analysis of resource use and comparison between the case study sites on the chosen outcomes, whilst also allowing us to build an understanding of processes of care (specifically those that support continuity of care and integrated working). This mixed methods approach will enable us to interpret quantitative measurements and understand how the presence or absence of key features/mechanisms have worked, for whom, in what context and at what cost.

**Methods**

**Phase one (10 months)**

The purpose of phase one is to develop a theoretical understanding and working propositions of how different contexts and mechanisms influence how the NHS works with care homes, paying specific attention to five outcomes of interest (see below). These propositions will be refined and tested in phase two.

The five outcomes of interest have been identified by the research team and its partner organisations as shared service priorities across the NHS, care home and LA organisations.

They are:

**1. Admission to hospital (including visits to Accident and Emergency)**

The extent to which residents are enabled to avoid hospital admission and remain in the care home can reflect care home staff confidence and their access to services, support and guidance provided by health care services and related frameworks of care in use. Repeated admissions towards the end of life can also be reduced where proactive
collaborative advanced clinical planning is embedded within systems of care.

2. Length of stay in hospital for all conditions

Often the decision to admit an older person to hospital is appropriate and cannot be avoided. However, the length of hospital stay is influenced by how easy it is to discharge the older person to the care home which in turn is influenced by the relationship between care homes and primary care services, and the relationship of both with secondary care.

3. Use of Out of Hours Services (OOH)

Use of out of hours service can be an indication of the level of anticipatory care, joint planning, level of day to day NHS support received, and care home staff capacity, confidence and ability to deal with residents’ unexpected health care needs.

4. Medication Use and review

The majority of care home residents take 7 or more medications. Evidence suggests that residents are vulnerable to prescribing and administration errors and that review of medication using agreed criteria (e.g. STOPP criteria Parsons 2011) can improve the quality of prescribing and medication use. Regular review can also highlight other issues and act as a surrogate for proactive relevant care.

5. User satisfaction

Older people, including those with some cognitive problems, can express what is important to them in their health care, their preferences for who else is involved in discussing health care decisions (family and care home staff) and who takes responsibility for the day to day management of their health care. Satisfaction with care in this setting needs to include the multiple perspectives of resident, family member and care home staff as recipients of health care services.

Phase one has two strands of enquiry

1. Stakeholder interviews

2. Synthesis of the evidence on how the NHS has operationalised working in and with care homes .

Stakeholder Interviews (3 months):

The priorities of the NHS for cost management and concerns about appropriate use of resources and service efficiency are well known. There is, however, less clarity about what level of evidence commissioners want or use to make judgments about services to care homes, what are believed to be effective when working in and with care homes and how contexts of care influence demand on NHS services (e.g. History of provision, size of care homes, leadership, care homes with on site nursing and those without). There is also a need to balance this with how care homes and their representatives, residents and relatives define the mechanisms of effective health care.

An interview schedule will be developed that will test and confirm with stakeholders what are known to be common approaches (and desired outcomes) in how the NHS works with care homes. Development of the content of the schedule and interview prompts will draw on work that the research team have completed, research on continuity of care and processes that support integrative working (Parker et al 2010,2011, Rosen et al 2011) and the expertise of the Study Steering Committee.

The interviews will address current patterns of commissioning and provision, examples of success and failure, how continuity of care is achieved, processes that support integrated working and the anticipated impact of policy change in a rapidly changing health care economy.

To capture a range of experience that reflects regional, historical and organisational differences we will recruit representatives of Resident and relatives (up to 5), NHS commissioners (n=3), senior managers from care home organisations (n=5), local authorities (n=3) and regulators (n=2). As there is a limited timescale for the resident stakeholder interviews we will undertake secondary data analysis on resident interviews from the APPROACH study to ensure a breadth of opinion and experience are captured. APPROACH looked at integrated working between primary health care and care homes. As part of the case study phase, residents were asked to discuss their health and the health care services they received. We will analyse these interviews to understand how residents described what they thought was important about the health services they received and how they defined effectiveness.

Findings from the interviews will refine the focus of the evidence review, clarify terms identify key headings or “theory areas” and linked questions that should be asked in the development of data extraction forms in the evidence review (Rycroft Malone et al 2010,2012).
Evidence review:
This will use a range of sources to establish a benchmark (from NHS and Care home evidence) of how the NHS works for and with care homes. The review process will enable us to develop propositions about specific Context Mechanism Outcomes threads that can be evaluated in phase two.
Care homes are often “hubs” of NHS service provision and although as many as 30 separate services may be linked to care homes, often only 2 or 4 services provide the core and ongoing support. To obtain a comprehensive overview of the range and frequency and type of NHS service delivery, we will review findings from surveys of NHS services in England provided to care homes (and where appropriate provided independently by care homes) completed since 2008.

This will include a synthesis of findings from the APPROACH national survey that focused on care homes without on site nursing, the 2010 CQC survey and a further BGS-funded analysis of PCTs and LAs about their health care provision to care homes. Local surveys commissioned by PCTs/CCGs, studies currently being completed by charities, other academic centres (e.g. EU funded SHELTER study University of Kent). This will include audits and related work completed by care home chains identified through the Care Home Providers Alliance and their members (e.g. ECCA) on health care provision and use of financial incentives.
This will include findings from the recently launched Big Care Home Conversation that relate to health care provision and recommendations from NHS Institute for Innovation and Improvement Care Home programme. Both of which aim to highlight best practice in care homes.
We will search for relevant publications and reports using methods that draw on principles of systematic review methodology: document retrieval, review and scrutiny by two researchers, information retrieval and analysis against the research questions. In addition we will search the grey literature using internet search engines across the nine government regions using search terms such as ‘care homes health care’ ‘older people health care homes, ‘health service provision care homes’. We have used this method to successfully locate organisation specific documents (Goodman et al 2011). We will also request information through primary care and care home other e-networks (e.g. My Home Life Network, National Care Home Research and Development Forum, HCPOnet, PCRN, DeNDRoN, Age and Aging networks), care home provider organisations and the Care Home Providers’ Alliance.
Data extraction will be organised to enable us to provide a summary of service provision in England by their frequency, location, focus and purpose, and, where possible, funding. It will provide the benchmark for what is commonplace, contextual information on service organisation and what is unusual or innovative for this sector by type of care home and provider.

Review of reviews: A review of published reviews on health care working with care homes and scoping of UK literature since 2006 will consider how mechanisms of service provision have been linked theoretically or empirically to the five areas of interest. We will use search methods as described above. This will include ‘grey literature’ from charities, SCIE, LAs, the regulator, care home organisations, on health care provision and guidance on health care for care home residents.

The findings, key themes, questions and approaches identified from the stakeholder interviews and team review will be used to structure the data extraction forms and identify the key questions or hypotheses that the review will address. The review process will make explicit the processes and players involved in providing the services the preferred mechanisms that cut across different models of service delivery in the key areas of interest. For example use of financial incentives, integrated care pathways, identification of specialist care home roles, facilitated learning) and how this is influenced by context (e.g. care homes with nursing, supportive provider organisation, presence of a clinical champion or long history of working with care homes). In keeping with realist synthesis equal consideration will be paid to negative and positive outcomes and inconsistencies in accounts of what works when and with what outcomes. Attention will be given to what is revealed about resident, relative and care home staff priorities and if they coincide with NHS accounts and narratives of good and bad care.

Analysis
Analysis will be organised to provide a narrative account of how services are delivered in England, including funding, frequency and location. The evidence review is theory led, purposive, iterative with ongoing stakeholder involvement
and the analysis is informed by the principles of realist synthesis methodology (Rycroft Malone et al 2012) Rycroft-Malone et al (2012) suggest there are four steps in the analysis and synthesis of data of a realist review. 1. Using the hypotheses and questions generated developed from the stakeholder interviews a detailed summary of the processes and the underpinning mechanisms and contextual factors identified will be completed. 2. Data will then be themed to reflect the observed characteristics of health care working in and with care homes (taking account of confounding evidence). 3. Connections between the extracted data and the themes will be examined and repeatedly tested according to the evidence to build a cumulative picture of the possible context mechanism outcomes that have a basis in the available evidence. 4. The development of propositions about different CMO threads that the evidence indicates supports effective working in some or all of the five outcomes of interest.

This exhaustive review of accounts, evidence and reviews of how health services work in and with care homes to achieve the outcomes of interest analysis will enable phase one to establish if the process occurred as described and where, when and for whom it was most effective. It will demonstrate the range of mechanisms used by the NHS to improve residents' care and through a process of theoretical abstraction propose the (counter) contexts in which they are more or less likely to be effective that will then be tested in phase two.

Findings and proposed features or mechanisms of interest supported (or refuted) by the evidence review will be debated with the research team the study steering committee, and where appropriate the networks they represent. This process of discussion will be carefully documented, and, drawing on the principles of nominal group technique (Carney et al 1996) will prioritize and confirm the contexts and mechanisms that are most likely to achieve the outcomes of interest. Key to this final analysis will be the development of a consensus on how the study findings differentiate between what are the mechanisms of service delivery to care homes and the contexts that support or inhibit that process. The findings from phase one will enable us to produce a list of propositions of the key mechanisms or features of service delivery (and the quality of the supporting evidence) and the different contexts, ranked according to evidence available, that have most influence on all or some of the five outcomes of interest. It will develop an account of the behaviour and interrelationships of the processes that are responsible for the change (Marchel et al 2012) and operational definitions to inform how they may be recognised and tracked within different models of service delivery to care homes. Whilst these cannot be specified with precision in advance they might be expected to include: detail about the level of resources and organisational endorsement (context) the activities involved e.g. evidence of regular review of residents; designated practitioners (mechanisms) and their impact on some or all of the outcomes.

A further deliverable from this phase will be a briefing document for care homes and commissioners on what services are available, accountability frameworks and models of care currently in place and how generalist and specialist services support care homes. This will be available on the My Home Life website and linked to other care home specific sites (e.g. ENRICH).

Phase one analysis will also provide a summary of data collection tools that are relevant and acceptable to the different stakeholders for use in phase two.

Phase Two
Phase two addresses research questions

1. How are these features/mechanisms associated with key outcomes, including medication use, use of out-of-hours services, resident and carer satisfaction, unplanned hospital admissions and length of hospital stay and costs of care?

2. How are these features/mechanisms associated with costs to the NHS and from a societal perspective?

3. What configuration of these features/mechanisms would be recommended to promote continuity of care for older people resident in care homes at reasonable cost?

Phase 1 will bring together what is known about how these mechanisms operate in reality and identify the propositions about how the NHS works in and with care homes that together are believed to be important.
The focus of phase two is dependent on the findings of phase one, based on our previous work, it is likely that certain contexts and linked mechanisms will be identified as significant in affecting some or all of the 5 outcomes of interest.

For example, evidence from APPROACH indicates that certain processes such as a designated clinician with shared access to electronic records and joint meetings, care home-based review of residents and use of review tools (for medication and nutrition) were perceived to have improved outcomes in these areas. In contrast, the Evidem end of life study and care home based work by MHL with Essex LA have shown that mechanisms such as facilitated discussion that support co design based approaches and shared problem solving can address context specific issues and priorities which can help to reduce uncertainty in the roles and responsibilities of different players, identify knowledge gaps and address issues of service capacity and resource need though may have less impact on outcomes such as medication and use of emergency services. Evidem eol, showed that changes in how GPs and DNs work with care homes reduced hospital length of stay and referrals to specialist services without a concomitant increase in primary care input.

Phase two will use a case study design to develop further understanding of the interrelationships between the Identified CMOs of interest and enable us to test propositions from phase one.

It will adopt a longitudinal case study methodology to describe the detail and compare the delivery of continuing healthcare to care homes and their residents across three geographically discrete sites where care is defined respectively by service delivery models that have the perceived prerequisites for optimal care and where they are not present within existing service delivery to care homes.

**Sampling and Recruitment**

The sample will be built up in three stages:

**Identification of participant geographical areas**

Using the findings from in phase one to drive site selection we will use, our existing links with health and social care services across England, to locate suitable sites. Currently members of the team have robust working relationships with Hertfordshire, Cambridgeshire, Essex, Bedfordshire, Nottinghamshire, North, South and West London, Lancashire and Sussex primary care organisations and local care homes and care home provider associations. This is complemented by the *My Home Life* care home network and working relationships with 17 LAs.

- Two areas will be selected on the basis of models of commissioning and care delivery showing different context and mechanisms and features for which there is evidence of positive outcomes
- One area will be selected as an example of usual care, i.e. an approach to commissioning and care delivery for care homes in their area where either there is little or no differentiation between commissioning of services provided to people living at home and those in care homes or care home specific interventions are perceived as limited in scope and application.

We anticipate that areas will be identified by services where the behaviour and interrelationships of the processes of service delivery responsible for the change are characterized by the NHS providing services “to” care homes i.e. with minimal consultation and involvement of care homes, “with” care homes i.e. in collaboration with care homes and with opportunities for ongoing review or without any differentiation between older people living at home and in care homes, where clinician choice and preference determine how care is provided.

Thus, whilst all areas may use, similar mechanisms to provide care e.g. designated personnel (specialist teams, clinical champions, regular named clinicians) the contexts in which they are provided will differ (use of financial incentives, involvement of the care home manager, facilitated training and support, history and stability of post, frequency of clinician engagement and network of care). Phase two will demonstrate what is context specific and what is effective for some or all of the five outcomes of interest.

Areas will be defined by the NHS provider organisations that has responsibility for care homes across a discrete geographical area, and where possible the linked CCG.

**Familiarisation and Recruitment: 6 months**

To identify and describe the services in the three areas and the four care homes we will have meetings and interviews with managers with lead responsibility for older peoples’ care in health and social care, and field-visits to
Based on previous studies we anticipate having discussions with up to five provider areas to recruit three for the study. This time will also be used to familiarize the research team with the sites and hold preliminary discussions with relevant clinicians and care home providers about proposed data collection tools and the level of involvement required.

Selecting and recruiting homes for involvement in the study

Four care homes from the area that offers usual primary care/community services and 4 in each of the two areas that have models of service delivery that are characterized by the CMO threads of interest that were identified in phase one.

Although the identification of service delivery models is theory driven, based on the findings of phase one we will focus as far as is possible upon “typical” homes, i.e. those: with 25 beds or more (median size of care homes with and without nursing provision is 25 and 48 beds respectively); and identified as having contact with a range of NHS services comparable to the common patterns of service delivery identified in phase one. We will aim to recruit care homes from a range of ownerships.

We will exclude care homes: with specialist registration for alcohol and drug abuse or learning difficulties; those with bed numbers outside the interquartile range; those whose manager has been in post for less than six months; those providing specialist care services commissioned by the NHS; and those where more than 50% of residents are self funding (self-funded residents often experience lower dependency and personal care needs Challis et al 2007). All remaining homes that have contact with the services of interest will be sent a letter inviting them to participate in the study.

From the care homes willing in principle, to participate in the study, the care homes will be selected to include those with and without onsite nursing and registration for dementia care. To enhance opportunities for comparison and to produce case studies with resonance to the broader English care home sector. We will aim as far as is possible, to match the first four care homes recruited in the area where usual care is provided with the remaining eight care homes in the two CCGs for resident population, staffing ratios and proximity to secondary care.

Support for recruitment and participation will be achieve through local PCRN and DeNDRoN offices and interested care homes will be helped (if not already a member) to join the newly established Enabling Research in Care Homes (ENRICH) network that has been initiated through a collaboration between DeNDRoN and the Dept of Health.

The ENRICH initiative offers support and advice for clinicians, academics and care homes on participating in research in care homes. 2012 will see the start of a network of care homes that have nominated staff that will liaise with research teams, support recruitment to studies, provide access to data and be familiar with social care governance requirements and processes for the recruitment of people who may not have mental capacity to consent to have their notes reviewed.

To ensure that residents’ care is not compromised by care homes’ participation in research, the ENRICH initiative has also provided guidance for reimbursement of care staff time when supporting research. Currently, ENRICH care homes are being developed in North Thames DeNDRoN, Sussex Coast, North West and Thames Valley (SI and CG are members of the ENRICH programme board) Discussions with the leading care home providers to have corporate membership of ENRICH are likely to extend the reach of the network.

Recruiting residents from participant homes

The challenges of recruiting older people to research in care homes is well documented (Goodman et al 2011c; McMurdo et al 2011) Based on previous studies and with the support of ENRICH and public involvement in research (PIR) members who have worked with us on two studies to introduce research to residents and relatives we would aim to achieve close to 100% recruitment of the remaining residents and a minimum of 60% recruitment. Where residents lack mental capacity and have no consultee, or whose consultee cannot be contacted, to maximize recruitment we will
put in place a robust protocol that will include the use of nominated consultees. Those residents attending for respite only, or who are recognised as terminally ill (i.e. in the last weeks of life) will be excluded.

**Sample size**

Based upon three areas and the purposive sampling framework outlined we would expect to recruit a resident sample of 263-438 based on 60-100% recruitment. Our target number of care home staff will be 60 (5 per home) to reflect a range of seniority and skill and, depending on GP attachment and models of service delivery, between 2-3 GPs, 2-3 NHS nurses (district nurses/specialist nurses) and 2-3 therapists per home – representing a maximum of 168 participants. Where possible we will interview the chair of the participating CCG (n=3) and the Health and Wellbeing Boards (n=3) about current and projected patterns of service delivery to care homes.

**Conducting the Case Studies**

The longitudinal mixed method design enables us to track the impact of the mechanisms or features of interest, taking a wider perspective in order to understand what works and why, for which groups of residents, when and in what context. This element of the project thus adds a process evaluation, where we can describe experiences of those who have received the different approaches to service delivery. It enables us to study if particular residents (e.g. high resource users) benefit more or less from the different mechanisms of care provision being studied and how if there are differences in responsiveness and flexibility as residents’ needs change over time.

Data collection will last 12 months.

**Resident baseline descriptors:** derived from care home records and will provide a basis of describing similarity or heterogeneity of the population studied in different homes. These will include on the five areas of interest (medication review and use, out of hours service use, hospital admissions, length of stay in hospital, and any documented evidence of user satisfaction where available). In collaboration with the care home staff, and following piloting, we will use an existing tool that is a subset of interRAI Minimum Data Set assessment items to record information on resident clinical and functional status (Mor 2004) (see end of document). It combines assessment items relating to clinical characteristics with ADL and cognitive function that relate to staff care time (Carpenter 2003) Widely used, internationally validated, ready formulated, this will provide the study with cross-national comparability and based on the experience of the Shelter study we know that it is clinically feasible to complete by care home staff (including care assistants who receive training from the research team).

**Descriptive case studies of continuing care as delivered to care home residents:** This will be an iterative process and will take account of: tape-recorded interviews with residents and family members care home staff commissioners, GPs, NHS nurses, allied health professionals, observation and documentary analysis of NHS and care home policies and procedures. With the exception of residents and relatives, participants will be interviewed at least once over the twelve months and key informants from the different groups, up to three times over the course of the year. (Details of residents and relatives interviews are given in a separate section). Interviews will be semi-structured and use as their reference point phase one findings. In addition to the five outcomes of interest, data from interviews will also explore the transferability of Parker’s work on the components of continuity of care and Rosen (2011), Shaw et al (2011) work on integrative processes both of which highlight that service provision can only be meaningfully understood from the level of the patient or, in this case, resident.

**Resource-use outcome measures** A bespoke proforma for collecting service use data complementary to the Inter-RAI and RUGs, will be developed with the participating care homes and used to collect data on community services that visit the care home for any resident. This will include data on frequency and duration of visits. The APPROACH study found that up to 30 different services (excluding GPs) visited care homes and a small number of them used by many care homes and a lot that were infrequently accessed. Findings from initial discussions and the baseline measures will be used to select the specific services that will be recorded for residents on a monthly basis alongside the other elements of service use (e.g. GP visits frequency and duration) and the five areas of care. On a monthly basis we will visit the care homes maintain working relationships with the care homes and prospectively collect data on the five areas of care resident admissions to hospital (number and duration); emergency department attendances; and out-of-hours GP and ambulance calls. Two designated member of the care home staff will have responsibility for day to day data collection.
on resource use, key events and contact with NHS services. These data will be checked and details clarified by researchers from care home records and in discussion with the member of care home staff. We will do a 10% reliability check with residents’ GP records. Patient level service use data will be converted to costs by multiplying each item of utilization by the appropriate nationally validated unit cost (Curtis 2011). Costs for each item will be summed to generate a total cost per resident over the 12 month observation period. Booked Interviews with different participants (GPs DN, therapists) will also be completed by the researchers as part of their monthly visits.

**Resident interviews and where appropriate their family representative on satisfaction (user outcomes):** These will be conducted in the second half of data collection and take account of resident and family members overall satisfaction with continuing healthcare services. A semi-structured interview schedule will be driven by the findings from phase 1 about residents’ priorities for health care and continuity of care. Interviews will be conducted with up to 60 of the residents in the 12 care homes.

Care home staff satisfaction surveys (staff outcomes): These will be conducted at the completion of data collection and take account of staff members’ overall satisfaction with continuing healthcare services. The composition of the survey will be driven by the outputs from phase 1 and what is known about continuity of care and key integrative processes. It is anticipated that it will be a single-side of A4 and comprise 5-6 questions. Arnetz and colleagues in Stockholm used a 4 point Likert scale to quantify satisfaction with aspects of healthcare provision including: information about illness; information about routines; security; accessibility; diagnosis and care. Initially developed as part of a quality improvement tool for patient completion in acute hospitals, it has been used in a variety of settings including community-based care and for completion by staff, with excellent internal consistency and good correlation between staff and patient responses. “Analysis will also test the wider usefulness of the tool for review of service provision in care homes.

**Analysis and Synthesis**

To enable comparison Home, resident and staff level data will initially be analysed and reported separately with quantitative data including resource use and costs reported using basic descriptive statistics, and compared across areas and care homes. A matrix (O’Caithlin et al 2010) will be generated, with the rows representing individual homes and columns organised to reflect the key propositions developed from phase one as well as the data generated from resource use and level cost outcomes. This will allow qualitative cross-case analysis taking account of similarities and differences between individual homes. And what the data reveal about the interrelationships between the mechanism and context of care. Attention will also be given to the linked process outcomes of interest i.e, continuity of care and patterns of integrated working (Parker et al 2011, Rosen et al 2011).

Analysis will be iterative and reflect the analytic stages followed in phase one. It will focus on what is revealed about the actual intervention or mechanism, the observed outcomes and the context conditions and any, previously undocumented underlying mechanisms (Marchal et al 2012) This will be compared with the theoretical propositions from phase one to establish the conditions where the mechanisms work (or not) and their transferability across different settings.

Quantitative data analysis will be conducted within the confines of the case study design. For each case study home, the characteristics of the residents recruited and not recruited to the study will be compared to understand the implications of any differences in recruitment. Descriptive statistics will also be used to compare the baseline characteristics of recruited residents from each care home using items collected from the InterRai tool. This will allow comparisons to be made about the similarities and differences of the care homes recruited within and between different service delivery models, and provide the context for the subsequent analysis of outcomes.

For each recruited resident the number of contacts with primary care (GP, practice nurse), community services (district / specialist / mental health nurses, physio / occupational / speech and language therapists, other), and out of hours services will be separately summed over the 12 month observation period. Total use of ambulance services, A&E, hospital outpatient and inpatient (number of admissions and length of stay) will also be computed. Service use for each item will be converted to costs using validated national unit costs data Curtis 2012; Dept. of Health, 2011). Costs will be
summed to provide a total cost for primary and community care, secondary care, and overall. Descriptive statistics will be used to summarize these data for each care home, with particular focus on the study resource use outcomes (use of out of hours services, unplanned hospitalizations and lengths of stay). For recruited residents who do not complete the follow-up period due to death, move to a new care home or withdrawal from the study, statistics on resource use will be calculated on a pro rata basis. Data will be summarized separately and explored for these residents.

High users of the key service use outcome variables will be identified so that variability between care homes, and within and between service delivery models, with respect to the mechanisms established in phase 1, can be explored. These key outcomes will also be described and compared according to different subgroups, defined after the completion of phase 1, to investigate which mechanisms work for which groups of residents in which contexts. Similarly, appropriate descriptive statistics will be used to explore the other main outcome variables (medication reviews and resident and carer satisfaction), and any emerging findings from the qualitative data.

To help inform these descriptive analyses, regression modeling (after adjustment for non-normality in the distribution of costs) will be used to investigate which resident characteristics are most strongly associated with costs (separately for total, primary and community, secondary care costs), accounting for clustering in the outcomes within care homes.

**Anticipated outputs:**

1. A specification for services to care homes – highlighting the key mechanisms and features which are central to optimal care and those which are not.
2. An understanding of how each service described impacts upon key NHS resource use variables.
3. Cost implications for each service studied which will allow commissioners to consider the cost-and consequences of implementing the models with their attendant features or mechanisms.
4. A reproducible questionnaire/promt guide that commissioners/managers can use to evaluate resident and/or family satisfaction with healthcare interventions.
5. Feasibility data on the care home staff satisfaction study, such that commissioners may be able to use this to evaluate care home staff satisfaction with healthcare interventions.
6. Study findings will both equip care homes to work strategically with the NHS and make explicit what can be defined as a reasonable and effective service and the processes that need to be in place to achieve it.

**Contribution to collective research effort and research utilisation.**

Partnerships with the three health communities involved in this project give opportunities for shared learning between the research team, commissioners and care home providers. It has also placed care homes as equal collaborators at each stage and we anticipate will directly change how information and learning is shared, creating opportunities) to incorporate learning and mechanisms that come from care home centred work as well NHS and LA initiated services.

There are three days for feedback to participants when commissioner and provider managers from the three CCGS will meet together with the research team to review emerging findings more formally, offering opportunities for learning and development across the sites. On the APPROACH study a similar event was able to offer online access for care homes and staff unable to attend. Participants with access to a computer could view presentations, hear discussions and email questions direct to speakers and participants in real time. It proved a useful tool to link geographically dispersed and isolated care providers and is one that has potential for the involvement of residents.

As well as interim and final reports to NIHR SDO, we plan a series of academic outputs papers on the study findings.

The Study Steering Committee is crucial to this study. It offers opportunities for collective impact as it will contain health service managers, academics (e.g. Prof Carpenter) working with care homes clinicians, as well as representatives from LA (e.g Jan Lockyer,)care home organisations and residents and relatives representative groups. This group will advise on all aspects of the project, and will meet seven times over the period of the study. The research team has good links with all these sectors and is confident (see supporting letters) that participation will be representative and its members fully engaged.

We will also work with the Public Involvement Group of UH who have experience of supporting recruitment to care home studies (Goodman et al 2011b) reviewing study materials and contributing to the critique and dissemination of
Finally, we will exploit opportunities for face-to-face knowledge transfer as they become available, through the different professional and practice networks of the research team.

**PLAN OF INVESTIGATION AND TIMETABLE**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research team set up meetings, Ethics approval for phase one, Confirmation of study steering committee</td>
<td>Completed prior to start of study</td>
</tr>
<tr>
<td>Stakeholder interviews</td>
<td>1-3m</td>
</tr>
<tr>
<td>Review of Surveys and Review of Reviews and related literature</td>
<td>3-5m</td>
</tr>
<tr>
<td>Analysis and identification of key features mechanisms and their configurations and circulation for wider discussion</td>
<td>4-7m</td>
</tr>
<tr>
<td>Documented discussion of findings by research team and study steering committee. Refinement of key propositions about NHS working in care homes.</td>
<td>8-9m</td>
</tr>
<tr>
<td>Submission of NHS ethics and governance (based on recent turnaround, assuming a 42-50 days per area for approval) and identification and recruitment of CCG and care homes where “usual care” is approach to service delivery</td>
<td>9-12m</td>
</tr>
<tr>
<td>Appointment of RAs Governance approval for all sites and familiarization with services and Recruitment of 12 care homes</td>
<td>10-15m</td>
</tr>
<tr>
<td>12m Data collection and interviews across 12 care homes</td>
<td>12-28m</td>
</tr>
<tr>
<td>Analysis and dissemination of preliminary findings</td>
<td>28-32m</td>
</tr>
<tr>
<td>Final Report Workshops and dissemination of findings</td>
<td>32-36m</td>
</tr>
</tbody>
</table>

**Ethical issues**

Ethical issues arise largely through the recruitment of older people with diminished mental capacity. The researchers working on this project are very experienced working with this group. Issues of informed consent also apply to the NHS, Care home and LA participants we will recruit, and information sheets and consent forms will be produced for them too. No individuals will be identified directly by us in research outputs, and any specific details about people’s circumstances or care homes/services that might make them recognizable will be removed or changed. The project will require both NHS research ethics committee and local NHS and social carer governance approvals. The process of gaining approvals will begin once notification of funding outcome is received to enable a rapid start to the work.

**Project Management**

**Phase one**: half-day, monthly meetings of the research team, leading and doing this work (CG, SD, CV AG JM) and meetings with the wider team every 8-10 weeks (face to face and teleconference) will be the main management tool for this project. **Phase two**: half day monthly meetings with members of the research team directly involved in the data collection and management across the CCG sites (AG CG SD JS HG JG LB) and the two RAs appointed to the project and meetings every 8-10 weeks with the wider team. CG will have overall responsibility for delivery of the project to time and to budget. SD will act as the project manager, taking day-to-day responsibility for overall progress, ethics submission, data collection with part time research assistant support, in four care homes and for the liaison with the research team, study steering committee, public involvement in research groups and with residents and service providers. The wte input of CV, HG and LB will be greater at the beginning.
Professor Julienne Meyer (5%) will provide leadership in phase one to ensure that there is optimal participation and engagement in phase one from care home providers, their staff and resident and relative fora and representative bodies. She is particularly well placed to do this work through her work with MyHomelife, her direct link to policy makers and care home provider representatives. In phase two she will be actively involved in the development of care home appropriate data collection tools, analysis and critical review of findings. She will lead the work that supports the development of the DVD and the dissemination across the care homes.

Professor Christina Victor (2%) worked on the APPROACH study. She will take a lead for the organisation and analysis of residents’ and family members’ data in phase one and the development of how resident satisfaction is operationalised and assessed. She has a particular interest in how residents experience living in a care home, the contextual influence of family members on decisions by residents and care home staff to involve health care services, residents’ experience of loneliness and mental health how different approaches to providing health care in these settings may or may not address these issues. This will be focus of her involvement in the analysis of phase two data.

Professor Iliffe is an academic GP interested in primary care for older people, and a clinical commissioner in a locality group in inner London. He will provide guidance in phase one on the policy context, apply his experience in consensus methodology (particularly in phase one), contribute to the analysis of phase two and to the dissemination of findings to NHS services.

The Nottingham based researchers should be viewed as a linked team. Professor Schneider and Dr Gordon will provide co-supervision for the Nottingham-based research assistant. This will constitute twice monthly formal activity reviews provided by both supervisors in addition to ad hoc availability for any urgent issues. Prof Schneider is a full-time academic and, although Dr Gordon is a full-time clinician, his role as a Community Geriatrician (0.5 FTE) includes a time allocation for developing research within the community, including care homes, and he therefore will be able to provide additional support on a flexible basis. Prof Schneider and Dr Gordon have a track-record in working together on the Medical Crises in Older People Programme and have experience in supervising research assistants and students.

Professor Gladman is largely included in the bid as a contributor to project management meetings, data analysis and write-up but represents an additional, highly experienced mentor for the research assistant that can be drawn upon if required. He works closely with both Prof Schneider and Dr Gordon in both his academic and clinical roles.

In addition to the above support, there is an active community of care home researchers working within the Division of Rehabilitation and Ageing at Nottingham including those working as part of the Medical Crises in Older People programme, Falls in Care Home feasibility study, the Chair-based Exercise in Care Homes pilot, the Care-giver Communication Styles and Resident Behavior project and the Nottingham arm of the OT in Care Homes study. There are two monthly meetings of researchers from each of these studies, to allow sharing of experiences and ideas, and to establish an environment of mutual support.

Professor Gage will design the health economics data collection, devise the health economics analysis plan and supervise the work of the part time junior health economist who will carry out the analysis. She will work closely with Lucy Bradshaw the statistician in the project.

Clive Bowman, Finbarr Martin and Tom Dening join the research team for their expertise in geriatric medicine and their respective expertise in care homes (CB BUPA), professional representation of geriatric medicine and clinical involvement in care homes (FB British Geriatrics Society, clinician) and dementia, care homes and knowledge translation (TD). Their time is given without charge but they will be reimbursed expenses.

A carefully selected study steering group of relevant stakeholders, with an independent chair, will meet on seven occasions throughout the project. Membership will reflect the interests of residents, relatives, care home providers, NHS commissioners, LA representatives and providers and academics working in care home research.
Public and User Involvement

UH has a long-standing commitment to public involvement in research. This group has a coordinator based at UH, meets regularly to advice on proposed work, the design of research instruments and processes, the implications of results and effective ways of disseminating findings. Key members (Alex Mendoza, Marion Cowe, John Wilmott, Diane Munday) all have personal experience of family members living and dying in care homes and have worked on three previous NIHR-funded studies to support recruitment to studies through introducing the research at care home coffee mornings and through individual conversations with residents (Goodman et al 2011b). They are of similar age to many of the residents and all hold honorary contracts with the university. We have already discussed this proposal and have their support for the topic and the approach. Their input (as with previous studies in care homes) will be ongoing and participation will, as far as is possible (taking into account health and distances to care homes) be at each stage of the research process in phase one and phase two.

REFERENCES
Curtis L, Unit costs of health and social care 2010. www.pssru.ac.uk
Curtis L, Unit costs of health and social care 2010. www.pssru.ac.uk
English Community Care Association (2008) Can We Afford the Doctor? GP Retainers and Care Homes ECCA London pretty please
Parker, G., Corden, A. and Heaton, J. 2010 Synthesis and Conceptual Analysis of the SDO's Programme's Research on Continuity of Care National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre, Southampton


SECTION A. IDENTIFICATION INFORMATION

1. NAME
   a. (First) __________________________
   b. (Middle Initial) ______
   c. (Last) __________________________
   d. (Jr/Sr)

2. SEX
   1. Male
   2. Female

3. BIRTHDATE
   Year ____________ Month ____________ Day

4. MARITAL STATUS
   1. Never married
   2. Married
   3. Partner/significant other
   4. Widowed
   5. Separated
   6. Divorced

5. NUMERIC IDENTIFIERS
   a. Nursing home resident ID number
   b. Case Record Number

6. FACILITY / AGENCY PROVIDER

7. CURRENT PAYMENT SOURCES FOR INPATIENT
   0. No
   1. Yes
   a. Social Services
   b. NHS
   c. Self or family pays for full per diem cost
   d. Social Services with NHS co-payment
   e. Private insurance
   f. VA
   g. Other per diem.

8. REASON FOR ASSESSMENT
   1. First assessment
   2. Routine reassessment
   3. Return assessment
   4. Significant change in status assessment
   5. Discharge assessment covering last 3 days of service
   6. Discharge tracking only
   7. Other (e.g., research)

9. ASSESSMENT REFERENCE DATE
   20 ____________ Month ____________ Day

10. PERSON’S EXPRESSED GOALS OF CARE
    Enter primary goal in boxes at bottom

11. TIME SINCE LAST HOSPITAL STAY
    Code for most recent instance in LAST 90 DAYS
    0. No hospitalization within 90 days
    1. 31 to 90 days ago
    2. 15 to 30 days ago
    3. 8 to 14 days ago
    4. In the last 7 days
    5. Now in hospital

SECTION B. INTAKE AND INITIAL HISTORY
### 1. LEVEL OF CONTROL PERSON HAD OVER DECISION TO MOVE INTO LTCF
- Complete
- Some control
- Little or no control
- Could not (would not) respond

### 2. DATE STAY BEGAN
- [ ] [ ] [ ] Year
- [ ] [ ] Day

### 3. ETHNICITY AND RACE
- a. Hispanic or Latino
- b. American Indian or Alaska Native
- c. Asian
- d. Black or African American
- e. Native Hawaiian or other Pacific Islander
- f. White

### 4. PRIMARY LANGUAGE
- 1. English
- 4. Other

### 5. ADMITTED FROM AND USUAL RESIDENCE
- 1. Private home/apartment/rented room
- 2. Residential home
- 3. Sheltered housing
- 4. Mental health residence—e.g., psychiatric group home
- 5. Group home for persons with physical disability
- 6. Setting for persons with learning disability
- 7. Psychiatric hospital or unit
- 8. Homeless (with or without shelter)
- 9. Long-term care facility (nursing home)
- 10. Rehabilitation hospital/unit
- 11. Hospice facility/palliative care unit
- 12. Acute care hospital
- 13. Correctional facility (e.g., prison)
- 14. Other
  - [ ] Admitted from
  - [ ] Usual residential status

### 6. POSTAL CODE OF USUAL LIVING ARRANGEMENT PRIOR TO ADMISSION

### 7. LIVING ARRANGEMENT PRIOR TO ADMISSION
- 1. Alone
- 2. With spouse/partner only
- 3. With spouse/partner and other(s)
- 4. With child (not spouse/partner)
- 5. With parent(s) or guardian(s)
- 6. With sibling(s)
- 7. With other relative(s)
- 8. With non-relative(s)

### 8. RESIDENTIAL HISTORY OVER LAST 5 YEARS
- Code for all settings person lived in during 5 YEARS prior to date stay began [B2]
- 0. No
- 1. Yes
  - a. Long-term care facility—e.g., nursing home
  - b. Residential home or Sheltered housing

### 9. MENTAL HEALTH
- Record indicates history of mental illness or learning difficulties
- 0. No
- 1. Yes

### SECTION C. COGNITION

### 1. COGNITIVE SKILLS FOR DAILY DECISION-MAKING
- Making decisions regarding tasks of daily life—e.g., when to get up or have meals, which clothes to wear or activities to do
  - 0. Independent—Decisions consistent, reasonable, and safe
  - 1. Modified independence—Some difficulty in new situations only
  - 2. Minimally impaired—In specific recurring situations, decisions become poor or unsafe; cues/supervision necessary at those times
  - 3. Moderately impaired—Decisions consistently poor or unsafe; cues/supervision required at all times
  - 4. Severely impaired—Never or rarely makes decisions
  - 5. No discernible consciousness, coma [Skip to Section G]

### 2. MEMORY/RECALL ABILITY
- Code for recall of what was learned or known
  - 0. Yes, memory OK
  - 1. Memory problem
    - a. Short-term memory OK—Seems/appears to recall after 5 minutes
    - b. Long-term memory OK—Seems/appears to recall distant past
    - c. Procedural memory OK—Can perform all or almost all steps in a multitask sequence without cues
    - d. Situational memory OK—Both: recognises caregivers’ names/faces frequently encountered AND knows location of places regularly visited (bedroom, dining room, activity room, therapy room)

### 3. PERIODIC DISORDERED THINKING OR AWARENESS
- [Note: Accurate assessment requires conversations with staff, family or others who have direct knowledge of the person’s behaviour over this time]
  - 0. Behaviour not present
  - 1. Behaviour present, consistent with usual functioning
  - 2. Behaviour present, appears different from usual functioning (e.g., new onset or worsening; different from a few weeks ago)
    - a. Easily distracted—e.g., episodes of difficulty paying attention; gets sidetracked
    - b. Episodes of disorganized speech—e.g., speech is nonsensical, irrelevant, or rambling from subject to subject; loses train of thought
    - c. Mental function varies over the course of the day—e.g., sometimes better, sometimes worse

### 4. ACUTE CHANGE IN MENTAL STATUS FROM PERSON’S USUAL FUNCTIONING—e.g., restlessness, lethargy, difficult to arouse, altered environmental perception
- 0. No
- 1. Yes

### 5. CHANGE IN DECISION MAKING COMPARED TO 90 DAYS AGO (OR SINCE LAST ASSESSMENT)
- 0. Improved
- 1. Declined
- 2. No change
- 8. Uncertain

### SECTION D. COMMUNICATION AND VISION

### 1. MAKING SELF UNDERSTOOD (Expression)
- Expressing information content—both verbal and non-verbal
  - 0. Understood—Expresses ideas without difficulty
  - 1. Usually understood—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required
  - 2. Often understood—Difficulty finding words or finishing thoughts AND prompting usually required
  - 3. Sometimes understood—Ability is limited to making concrete requests
  - 4. Rarely or never understood
SECTION E. MOOD AND BEHAVIOUR

1. INDICATORS OF POSSIBLE DEPRESSED, ANXIOUS, OR SAD MOOD
   Code for indicators observed in the last 3 days, irrespective of the assumed cause
   0. Not present
   1. Present but not exhibited in last 3 days
   2. Exhibited on 1–2 of last 3 days
   3. Exhibited daily in last 3 days

   a. Made negative statements—e.g., “Nothing matters; Would rather be dead; What’s the use; Regret having lived so long; Let me die”
   b. Persistent anger with self or others—e.g., easily annoyed, anger at care received
   c. Expressions, including non-verbal, of what appear to be unrealistic fears—e.g., fear of being abandoned, being left alone, being with others; intense fear of specific objects or situations
   d. Repetitive health complaints—e.g., persistently seeks medical attention, incessant concern with body functions
   e. Repetitive anxious complaints/concerns (non-health-related)—e.g., persistently seeks attention/reassurance regarding schedules, meals, laundry, clothing, relationships

2. SELF-REPORTED MOOD
   0. Not in last 3 days
   1. Not in last 3 days, but often feels that way
   2. In 1–2 of last 3 days
   3. Daily in the last 3 days
   4. Could not (would not) respond

   Ask: “In the last 3 days, how often have you felt...”

   a. Little interest or pleasure in things you normally enjoy?
   b. Anxious, restless, or uneasy?
   c. Sad, depressed, or hopeless?

3. BEHAVIOUR SYMPTOMS
   Code for indicators observed, irrespective of the assumed cause
   0. Not present
   1. Present but not exhibited in last 3 days
   2. Exhibited on 1–2 of last 3 days
   3. Exhibited daily in last 3 days

   a. Wandering—moved with no rational purpose, seemingly oblivious to needs or safety
   b. Verbal abuse—e.g., others were threatened, screamed at, cursed at
   c. Physical abuse—e.g., others were hit, shoved, scratched, sexually abused
   d. Socially inappropriate or disruptive behaviour—e.g., made disruptive sounds or noises, screamed out, smeared or threw food or feces, hoarded, rummaged through other’s belongings
   e. Inappropriate public sexual behaviour or public disordering
   f. Resists care—e.g., taking medications/injections, ADL assistance, eating

SECTION F. PSYCHOSOCIAL WELL-BEING

1. SOCIAL RELATIONSHIPS
   [Note: Whenever possible, ask person, direct care staff, and family, if available]
   0. Never
   1. More than 30 days ago
   2. 8 to 30 days ago
   3. In last 3 days
   4. 4 to 7 days ago
   5. 3 to 4 days ago
   6. 2 to 3 days ago
   7. 1 to 2 days ago
   8. Not in last 3 days, but often feels that way

   a. Participation in social activities of long-standing interest
   b. Visit with a long-standing social relation or family member
   c. Other interaction with long-standing social relation or family member—e.g., telephone, e-mail

2. SENSE OF INVOLVEMENT
   0. Not present
   1. Present but not exhibited in last 3 days
   2. Exhibited on 1–2 of last 3 days
   3. Exhibited daily in last 3 days

   a. At ease interacting with others
   b. At ease doing planned or structured activities
   c. Accepts invitations into most group activities
SECTION G

1. SECTION G

1. ADL SELF-PERFORMANCE

Consider all episodes over 3-day period.

If all episodes are performed at the same level, score ADL at that level. If any episodes are scored with less than 6, score ADL as a 5.

Otherwise, focus on the three most dependent episodes or all episodes if performed fewer than 3 times. If most dependent episode is 1, score ADL as 1. If not, score ADL as least dependent of those episodes in range 2-5.

0. Independent—No physical assistance, set-up, or supervision in any episode
1. Independent, set-up help only
2. Supervision—Oversight/cueing
3. Limited assistance—Guided manoeuvring of limbs, physical guidance without taking weight
4. Extensive assistance—Weight-bearing support (including lifting limbs) by 1 helper where person still performs 50% or more of subtasks
5. Maximal assistance—Weight-bearing support (including lifting limbs) by 2+ helpers OR—Weight-bearing support for more than 50% of subtasks
6. Total dependence—Full performance by others during all episodes
7. Activity did not occur during entire period
8. Bathing—How takes a full-body bath/shower. Includes how transfers in and out of tub or shower AND how each part of body is bathed: arms, upper and lower legs, chest, abdomen, perineal area—EXCLUDE WASHING OF BACK AND HAIR.

2. LOCOMOTION/WALKING

a. Primary mode of locomotion
0. Walking, no assistive device
1. Walking, uses assistive device—e.g., cane, walker, crutch, pushing wheelchair
2. Wheelchair, scooter
3. Bedbound

b. Personal hygiene—How manages personal hygiene, including combing hair, brushing teeth, shaving, applying make-up, washing and drying face and hands—EXCLUDE BATHS AND SHOWERS

3. MAJOR LIFE STRESSORS IN LAST 90 DAYS—
e.g., episodes of severe personal illness; death or severe illness of close family member/friend; loss of home; major loss of income/assets; victim of a crime such as robbery or assault; loss of driving license/car

4. STRENGTHS

5. UNSETTLED RELATIONSHIPS

6. S. Long-Term Care Facility (LTCF) ©
### ACTIVITY LEVEL

a. Total hours of exercise or physical activity in LAST 3 DAYS—
e.g., walking.
   - None
   - Less than 1 hour
   - 1-2 hours
   - 3-4 hours
   - More than 4 hours

b. In the LAST 3 DAYS, number of days went out of the house or building in which he/she lives (no matter how short the time period)
   - No days out
   - Did not go out in last 3 days, but usually goes out over a 3-day period
   - 1-2 days
   - 3 days

### PHYSICAL FUNCTION IMPROVEMENT POTENTIAL

- **0. No**
- **1. Yes**

  a. Person believes he/she is capable of improved performance in physical function
  b. Care professional believes person is capable of improved performance in physical function

### CHANGE IN ADL STATUS AS COMPARED TO 90 DAYS AGO, OR SINCE LAST ASSESSMENT IF LESS THAN 90 DAYS AGO

- **0. Improved**
- **1. Declined**
- **2. No change**
- **3. Uncertain**

### SECTION H. CONTINENCE

#### 1. BLADDER CONTINENCE

- **0. Continent**—Complete control; DOES NOT USE any type of catheter or other urinary collection device
- **1. Control with any catheter or ostomy** over last 3 days
- **2. Infrequently incontinent**—Not incontinent over last 3 days, but does have incontinent episodes
- **3. Occasionally incontinent**—Less than daily
- **4. Frequently incontinent**—Daily, but some control present
- **5. Incontinent**—No control present
- **8. Did not occur**—No urine output from bladder in last 3 days

#### 2. URINARY COLLECTION DEVICE (Exclude pads/briefs)

- **0. None**
- **1. Condom catheter**
- **2. Indwelling catheter**
- **3. Cystostomy, nephrostomy, ureterostomy**

#### 3. BOWEL CONTINENCE

- **0. Continent**—Complete control; DOES NOT USE any type of ostomy device
- **1. Control with ostomy**—Control with ostomy device over last 3 days
- **2. Infrequently incontinent**—Not incontinent over last 3 days, but does have incontinent episodes
- **3. Occasionally incontinent**—Less than daily
- **4. Frequently incontinent**—Daily, but some control present
- **5. Incontinent**—No control present
- **8. Did not occur**—No bowel movement in last 3 days

#### 4. OSTOMY

- **0. No**
- **1. Yes**

### SECTION I. DISEASE DIAGNOSES

#### Disease Code

- **0. Not present**
- **1. Primary diagnosis/diagnoses for current stay**
- **2. Diagnosis present, receiving active treatment**

#### DISEASE DIAGNOSES

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[Note: Add additional lines as necessary for other disease diagnoses]

### SECTION J. HEALTH CONDITIONS

#### 1. FALLS

- **0. No fall in last 90 days**
- **1. No fall in last 30 days, but fell 31-90 days ago**
- **2. One fall in last 30 days**
- **3. Two or more falls in last 30 days**

#### 2. RECENT FALLS

[Skip if last assessment more than 30 days ago or if this is first assessment]

- **0. No**
- **1. Yes**

[blank] Not applicable

(first assessment, or more than 30 days since last assessment)
3. **PROBLEM FREQUENCY**
   Code for presence in last 3 days
   - 0. Not present
   - 1. Present but not exhibited in last 3 days
   - 2. Exhibited on 1 of last 3 days
   - 3. Exhibited on 2 of last 3 days
   - 4. Exhibited daily in last 3 days

   **BALANCE**
   - a. Difficult or unable to move self to standing position unassisted
   - b. Difficult or unable to turn self around and face the opposite direction when standing
   - c. Dizziness
   - d. Unsteady gait

   **CARDIAC OR PULMONARY**
   - e. Chest pain
   - f. Difficulty clearing airway secretions

   **PSYCHIATRIC**
   - g. Abnormal thought process—e.g., loosening of associations, blocking, flight of ideas, tangentiality, circumstantiality.
   - h. Delusions—Fixed false beliefs
   - i. Hallucinations—False sensory perceptions

   **NEUROLOGICAL**
   - j. Aphasia
   - k. Acid reflux—Regurgitation of acid from stomach to throat
   - l. Constipation—No bowel movement in 3 days or difficult passage of hard stool
   - m. Diarrhea
   - n. Vomiting

   **SLEEP PROBLEMS**
   - o. Difficulty falling asleep or staying asleep; waking up too early; restless; non-restful sleep
   - p. Too much sleep—Excessive amount of sleep that interferes with person’s normal functioning

   **OTHER**
   - q. Aspiration
   - r. Fever
   - s. GI or GU bleeding
   - t. Peripheral edema

4. **DYSPNEA (Shortness of breath)**
   - 0. Absence of symptom
   - 1. Absent at rest, but present when performed moderate activities
   - 2. Absent at rest, but present when performed normal day-to-day activities
   - 3. Present at rest

5. **FATIGUE**
   Inability to complete normal daily activities—e.g., ADLs, IADLs
   - 0. None
   - 1. Minimal—Diminished energy but completes normal day-to-day activities
   - 2. Moderate—Due to diminished energy, unable to finish normal day-to-day activities
   - 3. Severe—Due to diminished energy, unable to start some normal day-to-day activities
   - 4. Unable to commence any normal day-to-day activities—Due to diminished energy

6. **PAIN SYMPTOMS**
   [Note: Always ask the person about pain frequency, intensity, and control. Observe person and ask others who are in contact with the person.]
   - a. Frequency with which person complains or shows evidence of pain (including grimacing, teeth clenching, moaning, withdrawal when touched, or other non-verbal signs suggesting pain)
   - 0. No pain
   - 1. Present but not exhibited in last 3 days
   - 2. Exhibited on 1 – 2 of last 3 days
   - 3. Exhibited daily in last 3 days
   - b. Intensity of highest level of pain present
   - 0. No pain
   - 1. Mild
   - 2. Moderate
   - 3. Severe
   - 4. Times when pain is horrible or excruciating
   - c. Consistency of pain
   - 0. No pain
   - 1. Single episode during last 3 days
   - 2. Intermittent
   - 3. Constant
   - 4. Breakthrough pain—Times in last 3 days when person experienced sudden, acute flare-ups of pain
   - 0. No
   - 1. Yes
   - e. Pain control—Adequacy of current therapeutic regimen to control pain (from person’s point of view)
   - 0. No issue of pain
   - 1. Pain intensity acceptable to person; no treatment regimen or change in regimen required
   - 2. Controlled adequately by therapeutic regimen
   - 3. Controlled when therapeutic regimen followed, but not always followed as ordered
   - 4. Therapeutic regimen followed, but pain control not adequate
   - 5. No therapeutic regimen being followed for pain; pain not adequately controlled

7. **INSTABILITY OF CONDITIONS**
   - 0. No
   - 1. Yes
   - a. Conditions/ diseases male cognitive, ADL, mood or behaviour patterns unstable (fluctuating, precarious, or deteriorating)
   - b. Experiencing an acute episode, or a flare-up of a recurrent or chronic problem
   - c. End-stage disease, 6 or fewer months to live

8. **SELF-REPORTED HEALTH**
   Ask: “In general, how would you rate your health?”
   - 0. Excellent
   - 1. Good
   - 2. Fair
   - 3. Poor
   - 8. Could not (would not) respond

9. **TOBACCO AND ALCOHOL**
   - a. Smokes tobacco daily
   - 0. No
   - 1. Not in last 3 days, but is usually a daily smoker
   - 2. Yes
   - b. Alcohol—Highest number of drinks in any “single sitting“ in LAST 14 DAYS
   - 0. None
   - 1.
   - 2 – 4
   - 3. 5 or more

**SECTION K. ORAL AND NUTRITIONAL STATUS**

1. **HEIGHT AND WEIGHT**
interRAI Long-Term Care Facility (LTCF)

Section L  Skin Condition

1. Most Severe Pressure Ulcer
   - No pressure ulcer
   - Any area of persistent skin redness
   - Partial loss of skin layers
   - Deep craters in the skin
   - Breaks in skin exposing muscle or bone
   - Not codeable, e.g., necrotic eschar predominant

2. Prior Pressure Ulcer
   - No
   - Yes

3. Pressure of Skin Ulcer Other Than Pressure Ulcer—e.g., venous ulcer, arterial ulcer, mixed venous-arterial ulcer, diabetic foot ulcer
   - No
   - Yes

4. Major Skin Problems—e.g., lesions, 2nd or 3rd degree burns, healing surgical wounds
   - No
   - Yes

Section M  Activity Pursuit

1. Average Time Involved in Activities—e.g., alone, in social group
   - Most—more than 2/3 of time
   - Some—from 1/3 to 2/3 of time
   - Little—less than 1/3 of time
   - None

2. Activity Preferences and Involvement (adapted to current abilities)
   - No preference, not involved in last 3 days
   - No preference, involved in last 3 days
   - Preferred, regularly involved but not in last 3 days
   - Preferred, involved in last 3 days

   a. Cards, games, or puzzles
   b. Computer activity
   c. Conversing or talking on the phone
   d. Crafts or arts
   e. Dancing
   f. Discussing/reminiscing about life
   g. Exercise or sports
   h. Gardening or plants
   i. Helping others
   j. Music or singing
   k. Pets
   l. Reading, writing, or crossword puzzles
   m. Spiritual or religious activities
   n. Trips or shopping
   o. Walking or wheeling outdoors
   p. Watching TV or listening to radio

Section N  Medications

1. List of All Medications
   List all active prescriptions, and any non-prescribed (over the counter) medications taken in the LAST 3 DAYS
   [Note: Use computerized records if possible, hand enter only when absolutely necessary]
## For each drug record:

- **a. Name**
- **b. Dose**—A number such as 0.5, 5, 150, 300. [NOTE: Never write a zero by itself after a decimal point (X mg). Always use a zero before a decimal point (0.X mg).]
- **c. Unit**—Code using the following list:
  - gtt (Drops)
  - mEq (Milli-equivalent)
  - Puffs
  - gm (Gram)
  - mg (Milligram)
  - % (Percent)
  - L (Liters)
  - ml (Milliliter)
  - Units
  - mcg (Microgram)
  - oz (Ounce)
  - Other (Other)

- **d. Route of administration**—Code using the following list:
  - PO (By mouth/oral)
  - IM (Intramuscular)
  - IV (Intravenous)
  - Sub-Q (Subcutaneous)
  - rect (Rectal)
  - TOP (Topical)
  - TD (Transdermal)
  - IH (Inhalation)
  - NAS (Nasal)
  - OTH (Other)

- **e. Freq**—Code the number of times per day, week, or month the medication is administered using the following list:
  - Q1H (Every hour)
  - Q2H (Every 2 hours)
  - Q3H (Every 3 hours)
  - Q4H (Every 4 hours)
  - Q6H (Every 6 hours)
  - Q8H (Every 8 hours)
  - Weekly
  - 2W (2 times weekly)
  - 3W (3 times weekly)
  - 4W (4 times weekly)
  - 5W (5 times weekly)
  - 6W (6 times weekly)
  - (includes every 12 hrs)
  - 1M (Monthly)
  - 2M (Twice every month)
  - 3M (3 times daily)
  - 4M (4 times daily)

- **f. PRN**
  - 0. No
  - 1. Yes

- **g. Computer-entered drug code**—ATC or NDC

  [Note: Add additional lines, as necessary, for other drugs taken]

  [Abbreviations are Country Specific for Unit, Route, Frequency]

## 2. ALLERGY TO ANY DRUG

- 0. No known drug allergies
- 1. Yes

## SECTION O. TREATMENTS AND PROCEDURES

### 1. PREVENTION

- 0. No
- 1. Yes
  - a. Blood pressure measured in LAST YEAR
  - b. Colonoscopy test in LAST 5 YEARS
  - c. Dental exam in LAST YEAR
  - d. Eye exam in LAST YEAR
  - e. Hearing exam in LAST 2 YEARS
  - f. Influenza vaccine in LAST YEAR
  - g. Mammogram or breast exam in LAST 2 YEARS (for women)
  - h. Pneumovax vaccine in LAST 5 YEARS or after age 65

### 2. TREATMENTS AND PROGRAMS RECEIVED OR SCHEDULED IN THE LAST 3 DAYS (OR SINCE LAST ASSESSMENT IF LESS THAN 3 DAYS)

- 0. Not ordered AND did not occur
- 1. Ordered, not implemented
- 2. 1-2 of last 3 days

### TREATMENTS

- a. Chemotherapy
- b. Dialysis
- c. Infection control—e.g., isolation, quarantine
- d. IV medication
- e. Oxygen therapy
- f. Radiation
- g. Suctioning
- h. Tracheostomy care
- i. Transfusion
- j. Ventilator or respirator
- k. Wound care

### PROGRAMS

- l. Scheduled toileting program
- m. Palliative care program
- n. Turning / repositioning program

### 3. THERAPY/NURSING SERVICES IN LAST 7 DAYS—e.g., therapist or therapy assistant under direction of therapist

  [Note: count only post admission therapies]

  A. # of days treatment scheduled in the LAST 7 DAYS
  B. # of days administered for 15 minutes or more
  C. Total # of minutes provided in LAST 7 DAYS

  (or ordered if days administered = 0 and days scheduled > 0)

### Days Scheduled Administered Total minutes in last week

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<tbody>
<tr>
<td>a. Physical therapy</td>
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<td>b. Occupational therapy</td>
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<td>c. Speech-language pathology and audiology services</td>
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<td>d. Respiratory therapy</td>
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<td>e. Functional rehabilitation or walking program by licensed nurse</td>
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<td>f. Psychological therapy (by any licensed mental health professional)</td>
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### 4. HOSPITAL AND EMERGENCY ROOM USE

- Code for number of times in LAST 90 DAYS (or since last assessment if LESS THAN 90 DAYS)

  a. Inpatient acute care hospital with overnight stay
  b. Emergency room visit (not counting overnight stay)
**5. PHYSICIAN VISITS**
Number of days in LAST 14 DAYS (or since admission if less than 14 days in facility) physician examined person. Include authorized assistant or practitioner. Enter 0 if None

**6. PHYSICIAN ORDERS**
Number of days in LAST 14 DAYS (or since admission if less than 14 days in facility) physician changed person's orders. Include authorized assistant or practitioner. Do not include order renewals without changes. Enter 0 if None

**7. RESTRICTIVE DEVICES**
- 0. Not used
- 1. Used less than daily
- 2. Used daily—Nights only
- 3. Used daily—Days only
- 4. Used night and days, but not constant
- 5. Constant use for full 24 hours (may include periodic releases)

a. Full bed rails on all open sides of bed
b. Trunk restraint
c. Chair prevents rising

**SECTION P. RESPONSIBILITY AND DIRECTIVES**

1. **RESPONSIBILITY / LEGAL GUARDIAN**
   - 0. No
   - 1. Yes
     - a. Legal guardian

2. **How long person is expected to stay in the current setting or under the care of this service prior to discharge to community** (count from assessment reference date, including that day)
   - 0. 1-7 days
   - 1. 8-14 days
   - 2. 15-30 days
   - 3. 31-90 days
   - 4. 91 or more days
   - 5. Discharge to community not expected

**SECTION Q. DISCHARGE POTENTIAL**

1. **DISCHARGE POTENTIAL**
   - 0. No
   - 1. Yes
     - a. Expresses / indicates preference to return to or remain in the community
     - b. Has a support person who is positive towards discharge or maintaining residence in community
     - c. Has housing available in community

15. Deceased

3. **SCHEDULED TO RECEIVE HOME CARE SERVICES AT DISCHARGE**
   - 0. No
   - 1. Yes

**SECTION S. ASSESSMENT INFORMATION**

SIGNATURE OF PERSON COORDINATING/COMPLETING THE ASSESSMENT

1. Signature (sign on above line)
2. Date assessment signed as complete

**SECTION R. DISCHARGE**

[Note: Complete Section R at Discharge only]

1. **LAST DAY OF STAY**
   - 20

2. **DISCHARGED TO**
   - 1. Private home / apartment / rented room
   - 2. Board and care
   - 3. Assisted living or semi-independent living
   - 4. Mental health residence—e.g., psychiatric group home
   - 5. Group home for persons with physical disability
   - 6. Setting for persons with intellectual disability
   - 7. Psychiatric hospital or unit
   - 8. Homeless (with or without shelter)
   - 9. Long-term care facility (nursing home)
   - 10. Rehabilitation hospital / unit
   - 11. Hospice facility / Palliative care unit
   - 12. Acute care hospital
   - 13. Correctional facility
   - 14. Other

20

Year    Month    Day