Full title: Organising general practice for care homes: A multi-method study

Protocol version 1.0

Almost half a million people live in UK care homes. Most care home residents are aged and many live with multiple comorbidities including dementia and frailty. There is some evidence that access to and quality of health services for care home residents are not as good as in the wider community, and a growing consensus that change is needed. General practice provides first line medical services to care homes, but in recent years, innovative commissioning and service development have increased the variation in how general practice is organised for care homes. This study will examine different ways of delivering GP services to care homes, in order to identify those associated with the best outcomes for residents and staff.

Aim: To identify effective and cost-effective ways of organising general practice for care homes and evaluate the impact on residents' outcomes, general practice and care home staff.

Research Questions

- 1. In what ways is the organisation of general practice for care homes associated with better resident outcomes and experiences?
- 2. What are the implications of different models of GP involvement for residents' service use and costs?
- 3. What are the perspectives of residents, relatives and staff in general practices, commissioning organisations and in care homes, on different ways of organising primary medical services for care homes; which are acceptable and associated with positive experiences for staff, residents and relatives?

Background and Rationale

General practice provides first line medical care for care home residents in the UK. Proactive, holistic primary care offers the potential to reduce avoidable admissions to hospital, and enhance residents' health, wellbeing and quality of life. Yet, there is some evidence, and a widely held perception, that care home residents do not have equitable access to high quality primary care. There is great heterogeneity in the organisation of general practice services for care homes, both in the number of general practices providing services to an individual care home, and in nature, frequency and regularity of primary care contacts with a particular home. This project will address the question of whether and how the organisation of GP services impacts on care home residents' outcomes and staff experiences, in order to identify effective ways of serving this important group.

Care home residents have wide ranging care needs and require significant support from health services. People admitted to care homes are aged, with poor self-perceived health, functional impairments, and multiple co-morbidities including dementia. Median length of stay is 15 months and mortality rates in English care home residents are four times higher than those of community dwelling older adults. Patients with these characteristics make frequent use of health services. Research studies have described greater use of GP services by older adults in care homes, compared to people in their own homes, and more frequent hospital attendances. England has no routine, national data collection specific to the health and wellbeing of care home residents, but ad-hoc studies and evidence from elsewhere point to increasing age and dependence in care home populations.

The need to improve equity of access to and the quality of health services for care home residents has been acknowledged by the public and professionals. Previous small scale and qualitative studies in England have identified potential deficiencies in the process of GP care for residents, including a paucity of regular clinical and medication reviews and poor access to specialist dementia care.(1) There is also some evidence to suggest that the quality of chronic disease management in care homes is lower than in the community. Studies have described higher rates of potentially inappropriate GP prescribing and worse performance on some aspects of chronic disease management, for care home residents. It is estimated that half of all care home resident deaths in hospital could have been in the care home, which may point to a need to improve end of life care. Time pressures for GPs, relationships with care home staff, a lack of clarity over the boundaries of responsibility and the balance between reactive and anticipatory care are all identified challenges to improving care for residents. A structured, proactive approach to relationship building and working between care homes and general practices has widespread support from professional bodies and commentators. A recent evaluation of a shift to more regular, proactive care home visiting by one practice found that it did reduce hospital admissions.

Relationships between general practice and care homes vary at a number of different levels. Some care homes will have one general practice looking after all the residents. This may mean that people have to leave a GP they know well, when they move into a home. For older adults who have longstanding relationships with particular practices or clinicians, this disruption to relational continuity may be unwelcome and distressing. Research has found that access to GP services is associated with the approach to registering residents with GPs and the number of GPs working with a care home. Larger homes are more likely to encourage residents to switch GPs, and have one practice that serves all residents. General practices also vary in the frequency and regularity with which they schedule visits to care homes. Proactive visiting is expected to enhance the quality of care and reduce the need for ad-hoc GP visits and unscheduled hospital admissions. Care homes have been found to impact significantly on GP workload in some, but not all studies.

An understanding of the mixed economy of care in this setting is an essential basis for improving outcomes. Care home residents are supported by a variety of private and public funding, with services drawn from across health and social care boundaries. Some residents in homes with nursing, whose needs are judged to be predominantly medical, are fully funded by the NHS. Their care is provided by GPs working with care home nurses. Other care home residents are funded by the local authority or by themselves (or their families) depending on needs and means. Whilst their overall care is managed by their GP, those in (residential) homes without onsite nursing will receive

nursing care from a district nurse. In addition to NHS funding, a minority care homes pay a retainer fee to GPs for medical services or visits.

How best to organise primary medical care for care homes is a challenging question, and one that we propose to address by looking at patients' outcomes and experiences. General practice and care home staff facing different, competing priorities must form a team around the patient, across organisational boundaries. The organisation of this 'House of Care' around patients resident in care homes, most of whom will be living with at least one long term condition, lacks a firm evidence base. Care homes are challenging settings in which to implement the vision of dignified, person-centred care outlined in the Five Year Forward View. GPs are tasked with working in partnership with residents, helping them to find their voice, whilst working more efficiently, and integrating with other community and secondary care services. It is important to acknowledge that changes implemented to enhance the efficiency of general practice delivery in this setting may have adverse consequences for continuity and patient choice.

An ongoing NIHR funded study is using a realist review and data collection in 12 care homes, to look at the whole range of health service inputs and understand the features associated with positive outcomes. Other work has described the challenges of integrative working between care homes and the NHS. Our study will contribute to the evidence base for the development of new models of care, with robust data on the relationship between GP activity and resident outcomes. The findngs will complement the existing NIHR research portfolio, which has not addressed this specific question, or looked in detail at the relationship between general practice process and outcomes.

The Five-Year-Forward-View advocates for greater NHS support for frail older people in care homes, and new models of in-reach support. The Care Quality Commission and the British Geriatrics Society have both reported on deficiencies in the care provided to care homes and the need for enhanced quality of care. Despite much agreement on the need for change, there is little robust research evidence to guide commissioners and practices looking for new ways to improve the delivery of primary care services to care homes. In the absence of evidence, a number of different initiatives are being implemented. Six organisations were selected by NHS England in March 2015, to develop different ways of working with care homes in 'Vanguard' sites. They are all adopting different approaches. In one north east CCG, changes include a move to have only one general practice for one care home. In Airedale in Yorkshire, care homes have integrated telehealth links with the local NHS, which will have implications for the work of general practice. Beyond the structure of GP-care home relationships, there is another layer of potential variation, in the process of scheduling GP visits to residents. For many years, some GPs have chosen to conduct primary care 'ward rounds' in care homes, once or twice in a week, in a belief that this provides patients and care home staff with a better quality service, and this has been a feature of many local enhanced service contracts. Other practices maintain a responsive service to requests for visits.

The need for care home beds is predicted to increase in the coming decades. The oldest old are the fastest increasing section of the population, with a growing proportion of single person households. Already, one in six people aged over 85 years live in a care home, and they make up 60% of the resident population. By 2050, the number of older adults is expected to have doubled, many of whom will have no source of informal care. Precise forecasting of the demand for care home places is difficult, as it is also influenced by the availability of alternative services, welfare funding policies, market forces and older people's preferences. Nevertheless, it is likely that demographic shifts will lead to a rise in the number of people moving into care homes, greater care needs within homes, or both. General practice is also changing to meet patient expectations and adapt to a shrinking medical workforce. New structures and relationships, such as federations of practices, super practices and Multispecialty Community Providers, are emerging or proposed in response to the needs of local health economies. This is important contextual information, but irrespective of the exact format for the GP provider unit, an understanding of how to organise primary medical input to care homes will be essential, as the size of the ageing population grows.

Aims and objectives

Aim

The aim of this study is to identify effective and cost effective ways of organising general practice, to optimise outcomes for care home residents and evaluate the impact on general practice and care home staff.

This will be achieved through the following study objectives:

- To compare selected innovative ways of organising general practice for care homes and identify those associated with improved resident outcomes.
- To compare service use patterns and costs of selected ways of organising general practice for care home residents.
- To explore the perspectives and experiences of residents, relatives, staff in general practice, care homes and commissioniers on different ways of organising general practice for care homes.

Research Plan

Design and theoretical / conceptual framework

Primary care aims to be accessible, coordinated, person-centred, comprehensive, population orientated, as well as safe and of high quality. In this study, we will define quality of care to be the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. Our research will primarily focus on the instrumental goals of a health system (e.g. access to high quality care), but view them as a route to health, and a responsive service that offers patients choice, and treats them with dignity and respect. The Donabedian model for assessing the quality of health care services will provide a framework to guide our data collection and analyses in three dimensions; structure, process and outcomes. However, our findings and interpretation of the data analyses will be sited within the NHS House of Care Model, as this draws together the foundations of integrated care and continuity, and emphasizes a whole system approach that is central to care home work.

Case Study Approach

A multiple-case (embedded) design will be used. The rationale for using a multiple case design is for theoretical replication. Each individual case study consists of a 'whole' study and will generate data that will provide depth of understanding of GP service provision in care homes located within its physical, social, temporal, organisational and economic context. The findings from each case study will be compared across the case studies to determine both convergent findings (regardless of context) and divergent issues (dependent on context). The case studies have more than one unit of analysis because there are more than one individual being studied within the case study and more than one method used; therefore, the case studies have embedded units.

Setting / context

Three areas will be identified to act as case studies: two with new, contrasting ways of organising general practice for care homes, and one where there has been no systematic change from usual practice (multiple GPs per home). Although the case study area (Clinical Commisioning Group) will not be our primary unit of analysis, they will be used as a sampling frame. We are proposing to study the organisation of general practice services for care homes, but acknowledge that this is only one aspect of service input to care homes. By working with a small number of CCGs, we aim to keep constant as many other factors as possible.

Our approach to the selection of case study areas will be pragmatic, to take into account the rapid pace of change in this area, and the interval between submission of this application for funding and the start of the study. First, we will only consider data from practices that use one GP software package, TPP SystmOne and contribute to the ResearchOne database. TPP is now the second largest provider of GP software in the UK, with over 2500 practices in every area of the country and over five million anonymised health records are included in ResearchOne. Second, we will capitalize on funded new developments, when selecting case study areas. In March 2015, six organisations were selected by the NHS England to be 'Vanguard' sites, and lead the development of care models to enhance health in care homes. In three of these areas, a majority of the general practices use SystmOne software (Airedale NHS Foundation (16 out of 17 practices), Nottingham City CCG (40 out of 62 practices), and NHS Wakefield CCG (34 out of 40). In a fourth area, East and North Hertfordshire CCG, 20 of the 60 practices use SystmOne). Hence, Vanguard sites should be a rich source of practices with innovative models of care, for this study. Between the funding decision and project start, we will work with NHS England, the Vanguard sites, and the Vanguard evaluation unit, to select areas that have implemented the most clearly defined ways of GP working with care homes. A third case study area will be sought to be similar to the Vanguard site, but where there has been no systematic or wholesale change from usual practice, and multiple GPs provide care for a care home, with or without a regular pattern of clinics or visits. There are many potential candidates for the 'usual care' case site, but this will not be confirmed at this stage, as changes may be introduced between submission of this proposal and the start of the study.

To fully understand the different ways in which GP practices organise their delivery of services to care home residents, and to be certain that expected changes have been implemented, we need to look beyond the information in published organisational strategies. In all case study areas, we will interview lead commissioners for care home services as part of the study, to explore the contextual factors that underlie the

implementation of changes and anticipated benefits.

Research Plan

Step 1 We will conduct a brief email (with telephone follow up if necessary) survey with practice managers in each case study area. This will consist of a small number of questions that a practice manager should be able to answer without incurring any extra work. This survey aims to gather descriptive information about the organisation of practice services to care homes, including the number of care homes (with and without nursing) that a practice takes responsibility for, whether planned visits are made, which health disciplines are involved, an estimate of average weekly number of visits made to care homes, the existence of any financial arrangements with care homes, source of out of hours care and timing and nature of any innovations. We will use the findings to develop a typology of practice organisation, which we expect to contain a small number of categories, (made up of variables such as one practice for one care home, regular care home ward rounds, telehealth linkages, joint clinics with geriatricians). To identify practices with similar typologies we will undertake cluster analysis. The basis for a cluster analysis is formed by calculating the degree of similarity among the relevant variables of the different objects (practices) to be clustered. This procedure attempts to identify relatively homogeneous groups of practices based on the survey questions, without linking to potential outcome variables. The resulting categorization will be used as a unit of analysis in the quantitative analyses. It is anticipated that three to five clusters will be identified. We will provide the suppliers of our research dataset with a list of practices, their typology code, and individual survey responses, which will be linked to the anonymised dataset. It is important to note that we will be surveying all practices within case study areas, with no knowledge of which practice does or does not contribute to the research dataset, in order to maintain anonymity.

Step 2. Interviews with residents, relatives, general practice and care home staff, and commissioners

We will use qualitative methods to develop an in-depth understanding of staff, resident and their family perceptions and experiences of primary care in care homes. Up to 75 individual interviews (telephone or face-to-face) will be conducted with GPs (n=15), practice and care home staff (n=20), commissioners (n=10) and residents and family members (n=30). The interviews will be organised for a time and at a location most suitable for the participants. Participants (staff and commissioners) will be purposefully selected from the case sites (using information collected in the pre-study survey) to include representation from these staff groups, the models of GP services and geographical areas. Residents and family members will be purposefully sampled from across the case sites to represent a range of demographic characteristics, length of residency and care homes being served by the different models of GP service provision. The interviews will explore perceptions of the different models of general practice care, positive and negative consequences of different ways of working, how different models of care influence staff experiences, job satisfaction and resident and family experiences, and the underlying structures, processes and values that perpetuate these models.

Qualitative data (generated by interviews) will be analysed for thematic content. This approach is both inductive (data interrogated to answer research questions but themes allowed to 'emerge' from the data) and iterative (data collection and analysis occurring

simultaneously). Initially we will understand each case site and then we will explore similarities and differences across the case sites. Throughout this process, comparative analysis will be carried out; this method allows data from different participants to be compared and contrasted, such as GPs from different services, as well as comparisons of what GPs say compared with practice and care home staff, commissioners, residents and their families. Deviant cases will be actively sought throughout the analysis, and emerging ideas and themes modified in response. All of the interviews will be audio recorded (with participants' permission) and transcribed verbatim. Data analysis will involve a process of organising the data, descriptive coding, interpretive coding, writing and theorising. Data will be managed using a qualitative computer software package (NVivo 10). To promote quality, the following strategies will be used: description of the participants to provide context (credibility and transferability), transparency of the research process and use of theory (transferability), evidence of consistency using multiple examples from data (dependability), involvement of two members of the research team in data analysis, and engagement of the wider research team, informants and participants with interim findings (confirmability).

Step 3: Analysis of patient level data from general practice in the case study areas

Data from electronic health records in primary care will be analysed to compare achievement on selected measures, before and after the introduction of changes to GP organisation in two areas where innovations have been implemented, and over similar time period in a 'usual care' area.

We will work with pseudonymised, (de-identified) data, electronically extracted from contributing SystmOne general practices into the ResearchOne database. SystmOne is the second most widely used GP software system, used by more than 2300 of the 7900 general practices in England, covering a GP patient population of more than 15 million. Data are extracted from SystmOne into ResearchOne from consenting organisations, where patients have not opted out. ResearchOne now contains approximately five million GP patient records. The areas selected for study will have a sufficiently high proportion of practices contributing to ResearchOne to avoid concerns over anonymity. ResearchOne is accredited by a NHS Research Ethics Committee and the National Information Governance Board, and as the information is de-identified, Section 251 approval is not required.

Patient level data from GP records in the ResearchOne database will be extracted from each of the case study areas, using an existing algorithm developed to identify care home residents. The data extract will cover three years, from the time of data extraction, to ensure sufficient time for any changes in the organisation of GP care to be implemented. As median length of stay in a care home is 18 months, this strategy also aims to capture data from first admission, for people resident in a care home at the time of any innovation in GP care. Coded data will be extracted on repeat and acute medications, chronic disease management measures selected to be available in a high proportion of records (e.g. systolic blood pressure, HBA1C, BMI, total cholesterol/HDL cholesterol ratio, FEV1), coded long term conditions, the electronic frailty index, hospital admission, emergency department attendance, the number of primary care contacts. From the data provided, variables will be derived for potentially avoidable (ambulatory care sensitive) admissions and a measure of prescribing quality

(STOPP/START criteria). Approximately 4000 individuals will be extracted from the ResearchOne database. It is important to note that we aim to focus our study in a small number of geographical areas, but the exact number of case study areas will be kept under review, to ensure that we achieve an acceptable sample size.

Data analysis

We will have two related units of analysis, 1) our primary analysis will be the derived practice level code for the typology of practice organisation and 2) secondary will be case study area. In the case study areas where innovative practice has been introduced, we might expect that many or all practices will share the same typology, but this may not be the case. In the area where no systematic innovation has been introduced, we anticipate that there will be a range of typologies of organisation of general practice to care homes. The primary analysis aims to identify specific typology associated with 'good outcomes', the secondary analysis investigates whether there has been a general change at the area level without every practice changing their services.

Measures of health care utilization and process will be compared across the typologies and case study sites. The following will be presented: socio-demographic characteristics of the care home patient population, annual consultation and hospital admission rates per resident and practice; discrete data will be tabulated, continuous (normally distributed) variables will be described by mean and standard deviation (and confidence interval), continuous (non normally distributed) variables will be described by median and interquartile range. Data from the innovation date onwards will be used to compare with a pseudo-generated innovation data in the non-change typology areas to investigate the different typologies and identify outcomes showing clearest change. The pseudo-generated date of innovation will be generated from the existing knowledge of when case areas implemented change and will be generated based on practice and area characteristics. There was a very tight innovation window within the Vanguard areas, therefore this date is fairly fixed and relatively easily generated.

To investigate whether these typologies associated with change outcomes are independent of area or individual characteristics already in place prior to innovation change analyses of changes over time will be conducted. Using the time series data collected across a three year period analyses to detect a point of change around the introduction of changes to organisation (before/after) will be undertaken. This can be compared with the no change estimates to investigate 'real' versus 'cohort' change (using the pseudo-date for innovation) We will compare achievement on the specified measures of chronic disease management and use of medical services, with comparisons made within and across case studies. Multi-level regression models will be utilised to enable both practice and individual characteristics to be modelled, using logistic or logarithmic transformation as appropriate. Regression models for the time series data with parameters for the innovation implementation date will be modelled using Bayesian hierarchical change point (before/after) models, which allow for adjustment of individual level, GP level and area level covariates and estimate directly the impact of a change occurring at a defined time. Sensitivity analyses to the immediacy of any change will be investigated by shifting the known implementation date later to allow for a delay in any impact of change.

The economic analysis will focus on the differences in patient level costs associated

with resource use attributable to the changes in practice, within the two intervention sites and between the control and intervention sites. Individual patient level data for each site will be provided by the quantitative data, and used to construct an anonymised patient database showing utilisation of primary, community and hospital services. Each patient record will have costs assigned to the service use, using unit costs sourced from the PSSRU, NHS-Reference data, and where necessary, published literature. Cost of care for each patient, will be aggregated for a full year pre and post the change in service delivery at each site and used to calculate an average cost per patient for each time period and site.

Primary analysis will consist of a difference in difference analysis, comparing the change in annual costs per patient (pre and post) between each site. This is a pragmatic approach to allow each site to act as their own control, and to minimise the impact of nuanced differences in size and make up of each care home. Aggregating the data over a year will also help to smooth out issues such as seasonal variation and mortality rates. Additionally, a regression analysis will be applied to explore the change in average patient costs at each site, whilst controlling more directly for differences in baseline patient characteristics. Appropriate formulation of the regression model will be informed by initial descriptive analysis of the data. Primary analysis will be based on complete case data, however a secondary analysis will be conducted using multiple imputation to allow for missing data.

Synthesis of data analyses

Parallel mixed data analysis will be used to synthesise findings from the three work packages. Analyses of the data generated in each work package have been described above and will involve separate independent processes. Whilst these analyses are independent, each will provide an understanding of the organisation of general practice for care homes. These understandings (from these different sources) will be integrated to provide findings that are located within real-world contexts of health service delivery.

Dissemination and outputs

This research will identify ways of organising primary medical care for care homes that have a positive impact on residents' health and use of services. The care home sector continues to grow, and many residents' needs for support are complex, and ongoing. It follows that changes in service delivery that reduce the consumption of resources may lead to substantial cost savings for the NHS. Our findings will be of interest to commissioners who are advocating for changes in the delivery of primary care services in this sector. They will also be valuable for GP providers who are seeking efficient ways of managing their workload without compromising the quality of care delivered. For all audiences, our qualitative enquiry will provide an essential link between the production and effective implementation of evidence.

Dissemination activities will take place throughout the second year of the project, guided by the patient and public involvement representatives and the study advisory group. A project website will be established, to serve as a focal point for our online and social media activity, as well as emerging and definitive outputs. A project blog will be initiated during the project, with twitter feed from researchers sharing their experiences

and emerging findings. Our dissemination will be carefully tailored to the most relevant audiences, who are expected to be residents and relatives, policy makers, commissioners, professional bodes such as the Royal College of General Practitioners, the Royal College of Nursing and the care home industry. Accessible summaries of the research findings will be prepared for care home residents and their relatives with plain English summaries, online presentations and meetings. Here, our links with Age UK, ENRICH, the Residents and Relatives Association, the My Home Life Programme, the National Care Forum and other members of the National Care Alliance, will all be crucial to sharing our findings with a wide network of care home providers and staff, as well as residents and family members.

We plan to host a webinar towards the end of the project, to reach the broadest possible audience. In addition, short summaries of the study and its policy implications will be developed for hard copy and electronic dissemination, based on the successful model used by CRD at the University of York. These will be tailored to CCGs, the general public and policy makers.

Written outputs will be directed to two audiences. Summaries of our findings and their implications will be submitted to publications with a readership of commissioners and managers (e.g. Health Services Journal). Academic papers will be submitted for publication in peer reviewed general journals and those with a focus on elderly health care. National and international conference presentations will be sought, at events attended by decision makers; clinicians and researchers with a strong interest in older people and primary care.

Timetable

This is a two year project. High level milestones are shown below. They include obtaining approvals for interviews (month 1), start of interviews (month 2); completion of quantitative (month 21) and qualitative (month 18) analyses; completion of all outputs and initial dissemination activities (month 24). Dissemination will be ongoing and increasing in intensity throughout year two.

Project Month	Milestone
0	Project start
3	PPI meeting
6	Case Study 1 qualitative data collection, analysis and write up
	complete
9	PPI Meeting
10	Quantitative data analysis underway
11	Advisory Group Meeting
12	Case Study 2 qualitative data collection, analysis and write up
	complete
15	PPI Meeting, Advisory Group Meeting
18	Case Study 3 qualitative data collection, analysis and write up
	complete
21	Quantitative data analysis complete

High Level Milestones

22	PPI Meeting, Advisory Group Meeting
24	Synthesis of qualitative and quantitative data complete
24	Submission of report to funder
24	Webinar for NHS and care home stakeholders

Ethical committee approvals

Ethical issues – Interviews

Interviews will be conducted with residents, relatives and staff from general practice, care homes and commissioning organisations. The key risks to staff participants lie in failure to maintain confidentiality and anonymity. Interview responses that are perceived as critical of workplace, employer or colleagues may compromise the employment status or wellbeing of the participant. Hence, it is important that staff do not feel obliged to take part, and those who do consent to be interviewed, should be able to speak freely without fear of being identified in any of the outputs. To address these issues, the research team will conduct interviews by telephone or in locations chosen by the interviewees, and employers will not be informed which of their staff has participated. All research outputs will be anonymised, with particular care taken to ensure that specific details of the services discussed do not inadvertently identify individuals.

Interviews with residents and relatives may involve vulnerable older adults. Particular care will be taken to ensure consent is fully informed, and the interview process maintains residents' privacy. All interviews will be conducted in a manner that respects the rights and dignity of participants and ensures that their physical, psychological and social wellbeing are unaffected. Collectively, the applicants have wide ranging experience of qualitative research with older adults at the end of life, bereaved relatives and people with dementia and their caregivers.

Interviews with staff, residents and relatives will require approval from NHS and social care research governance authorities, and in the case of participants identified because they are patients, an NHS REC.

Ethical Issues – data analysis

The data to be analysed in this project are drawn from patient records in primary care. Although the dataset received by the research team will be anonymised, the highest standards of data security will be required. Inadvertent release of information from NHS records to third parties may cause distress and the breach of trust could compromise future research involving routine data sources and the reputation of the institutions and individuals involved. Any actual or potential patient identifiers will be removed before data are released to the research team, and information suppressed where the number of cases are small enough to risk identification. This work will follow the Caldicott principles, and comply fully with the legal requirements of the Data Protection Act. Access to the raw data will be restricted to members of the team directly involved in data analysis. Data will be encrypted, stored on a password protected computer, and backed up to an external hard drive kept in a locked filing cupboard.

Patient and Public Involvement

VOICENorth (Valuing Our Intellectual Capital and Experience) representatives will provide local input into our research. This organisation is supported by Newcastle University to harness the experiences and expertise of the older members of our community. Membership is open to any interested older adults, and now stands at around 3000. Individual members contribute to strengthening the relevance, quality and impact of Newcastle University research in a range of ways, and they regularly join research project groups.

The aim of PPI involvement is to ensure that the perspectives of care home residents and their relatives are represented fully in our work, and that our outputs are accessible and relevant to that audience. Our approach to the PPI role will be sensitive to the interests, time and capacity of the individuals involved. We will convene a specific subgroup of VOICENorth Members and meet with them regularly throughout the project. In addition, we will invite them to biannual review meetings. They will receive the agenda, papers and meeting notes. We will also organise separate meetings to work with them on interpretation of data analyses, the blog, plain English outputs, and the overall dissemination strategy.

Advisory group

An advisory group will oversee the research and expand the range of expertise contributing to the study. Terms of reference will be agreed at the first meeting of the group, but their role is expected to include advising on the research process, the relevance to the NHS and care home sector, and effective ways of influencing decision makers. Meetings will be arranged in (approximately) months 9, 13, 18.