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spru Social Policy Research Unit

EVALUATION OF SPECIALIST NURSING SUPPORT FOR CARERS OF PEOPLE WITH DEMENTIA

Summary of Research

Aims

1. Explore the processes, individual and system-wide impacts, and cost-effectiveness of specialist support for carers of people with dementia (using the largest such service - Admiral Nursing (AN) - as an exemplar).
2. Produce guidance to inform service delivery, organisation, practice, and commissioning of specialist support for such carers.

Objectives

1. Explore relationships between the characteristics of carers and people with dementia, AN service type and input, and outcomes.
2. Develop and test data collection methods to allow subsequent cost effectiveness evaluation.
3. Explore the cost-effectiveness of AN, as against usual care
4. Explore the perceived system-wide impact of providing specialist support services for carers of people with dementia, as against usual care.
5. Implement new data collection methods in AN (and that could be used by others) to facilitate future research.

Methods and analysis

Work package 1. Secondary analysis of AN's existing database to examine how AN service type, input and service users' characteristics and needs affect outcomes (objective 1). AN will provide an anonymised data set, with 22500 AN service user records since 2005. We will prepare the data set for analysis, carry out a range of uni-, bi- and multi-variate (regression) analyses, and establish the links between type and intensity of AN input, service user characteristics and needs, and outcomes. This will also inform subsequent stages.

Work package 2. Qualitative development work with carers in two areas with an AN service and two similar areas without a service will establish a data collection framework and processes for WP 3 (objective 2).

Interviews and focus groups will identify outcomes important to carers, and test the acceptability and feasibility of collecting data about these (via standardised measures) and resource use, to enable cost-effectiveness research in WP 3. This is vital, given the acknowledged challenges of evaluative research in dementia care.

Work package 3. Using this data collection framework, we will carry out a study of costs and effectiveness in areas with and without AN services. This will use innovative health economic methods and analysis (instrumental variable approach, Forder et al, 2013)) developed in a similar field - residential care for older people – where challenges of conventional evaluation also arise (objective 3).

Work package 4. Specialist dementia services' effects may extend beyond individual outcomes and resource use. Qualitative interviews with health and social care stakeholders in two areas with and two without AN services will explore the perceived system-wide impact of such carer services, as against 'usual care' (objective 4). Analysis will use the Framework Approach (Ritchie and Lewis, 2003).

Work package 5. Working with AN, and based on the data collection framework designed for WP 3, we will design a data collection framework to be implemented in AN (and elsewhere).

Work package 6. Produce best evidence guidance: A stakeholder workshop will present findings and develop best evidence guidance.

Outcomes and impact

1. Better service commissioning and delivery is a potential outcome of the best evidence guidance
2. Health or social care providers supporting carers of people with dementia could establish the cost-effectiveness of their services if they use our data collection framework of tested acceptability and feasibility
3. The partnership with AN will build research capacity in this third sector organisation to be further developed when the project is over.

References

Forder J, Malley J, Tower A-M, Netten A. (2013) Using cost-effectiveness estimates from survey data to guide commissioning: an application to home care. *Health Economics*, 23: 979-992. Published online 27th August 2013. DOI: 10.1002/hec.2973

Ritchie J, Lewis J. (2003) *Qualitative Research Practice: a guide for social science students and researchers,* London: Sage.

Background and Rationale

Carers are the mainstay of the support system for disabled and frail children and adults. The UK 2011 Census identified almost 6 million people who defined themselves as carers, over half of whom cared for more than 50 hours a week. In total, UK carers provide the equivalent of 17 million working hours of care per week. Further, both the population of carers overall and the proportion who provide the longest hours of care have increased since the 2001 Census[1].

Carers are most likely to be over the age of 50, more likely than others of the same age to report poor or indifferent health, and while people who become carers are more likely than others to be in poor health before they become carers[2], caring (further) affects both physical and mental health[3].

Carers of people with dementia are potentially an even more disadvantaged group than the generality of carers. They experience repeated transitions in their personal, social, economic and psychological lives as the dementia journey progresses, and a substantial literature has documented the impact of becoming and being a carer for a person with dementia[4]. They are more likely to report negative physical and psychological outcomes than otherwise similar carers who support people without dementia[5]. Spouses who care for partners with dementia are themselves often elderly and frail, while those who care for parents may also still have responsibility for their own children.

Without carers, the health and social care system would be hard pressed to provide alternative care for people with dementia. However, as outlined in the Commissioning Brief for this NIHR HS&DR call, evidence about how best to support carers through the dementia ‘journey’ remains elusive. This is largely due to the relative paucity and poor quality of existing evaluative research[6]. A particular weakness in the evidence base is the lack of studies that can throw any light onto the cost-effectiveness of interventions to support carers. Where there is evidence of effectiveness there is rarely evidence of costs, whether to health and social care services or to carers and families themselves.

There is one dementia-specific, specialist nursing service that targets support at the carers of people with dementia – Admiral Nursing – and it is this that we propose to evaluate here.

What is Admiral Nursing and what do we know about its impact?

Admiral Nursing (AN), based within the charity, Dementia UK, is the only UK-based, dementia-specific, specialist nursing service that targets carers of people with dementia. The service was first piloted in Westminster in 1990 and currently provides support via more than 65 teams around the country.

AN services vary in their composition, remit, funding models, case mix and other key characteristics, although all work to a core set of values to support carers and family members of people with dementia. Some are commissioned and/or hosted by the NHS, others by local authorities or third sector organisations. AN services are currently found in memory assessment services, community AN teams, care homes, hospitals, palliative and end of life care settings, and third sector settings. The service also runs a national helpline (Admiral Nursing DIRECT) which was established in 2008.

Dementia UK describes the AN service thus:

> *Admiral Nurses are specialist dementia nurses who work closely with families living with the effects of dementia. They provide psychological support, expert advice and information to help families understand and deal with their thoughts, feelings and behaviour and to adapt to the changing situation. Admiral Nurses seek to improve the quality of life for people living with dementia and their families by using a range of interventions to help people live positively with the condition and to develop skills to improve communication and maintain relationships. Admiral Nurses also uniquely join up different parts of the health and social care system and enable the needs of family carers and people with dementia to be addressed in a coordinated way. They provide consultancy and education to professionals to model best practice and improve dementia care in a variety of care settings (Dementia UK 2014-17 Strategic Plan[7]).*

All Admiral Nurses are mental health nurses who have specialised in the care of people with dementia. However, while they do work with people with dementia, their main objective is to support carers and family members of the person with dementia.

A recent systematic evidence synthesis scoped the existing literature about AN to determine, among other things, the scope, nature and key attributes of the AN role[8]. This work identified two main themes that underpinned ANs' work with carers:

- relational support (including taking a carer-centred approach, providing individually tailored support, and being a 'friend') and
- co-ordination and personalisation of support (including facilitating access to other services and support, collaborating with other service providers, and advocating on the carer's behalf).

A third theme related to organisational and delivery issues, including the management of case loads, providing care across the dementia journey, definition of the role, and the dynamics of relationships with other parts of the health and social care system for people with dementia.

The synthesis suggested that carers value the emotional support and education that ANs provide and that their expectations of what ANs might provide and what they actually do provide largely match. However, it also pointed out that while there has been qualitative evaluation of AN in the past[9], the evidence base on its effectiveness, costs, cost-effectiveness and relationships to other health and social care services is very limited.

The HS&DR Commissioning Brief refers specifically to AN and this earlier evidence synthesis; we have built on this and our existing partnership with Dementia UK to develop a rigorous quantitative and qualitative approach to address our main research question:

> What are the costs and benefits for carers, families and people with dementia of providing specialist nursing support?

In addressing this question, we will also explore the wider effects for health and social care of specialist support services for carers of people with dementia, and the impact that receiving services has on carers' navigation of other parts of the health and social care system.

Why this research is needed now

There have been some studies of AN, but predominantly small-scale and descriptive and none has explored cost-effectiveness. The recent evidence synthesis, commissioned by *Dementia UK* itself, showed that few studies provided evidence about outcomes for carers or evaluated the specific inputs of AN services[8]. Looking beyond AN, the synthesis also found little clear evidence about the cost effectiveness of other models of community-based support for people with dementia and their carers.

The implications for research outlined in the synthesis included the need to:

- evaluate the specific input of AN practitioners, set alongside outcomes for carers;

- explore the in-reach and training role of AN to acute hospitals, care homes and other practice settings and practitioners;
- investigate the contribution of AN services from the perspectives of other health and social care stakeholders;
- understand the profile of carers that AN services support.

The work we propose here will throw light onto all these issues.

However, as the authors of the synthesis point out, as others have experienced[10] and as we know ourselves from our current research on an intervention in dementia care[11], there are substantial challenges in setting up and carrying out evaluation of complex interventions, and particularly in the area of dementia care.

Reflecting both the lack of current evidence and the difficulty of generating new evidence, our proposed project has a dual purpose. The first is to make best use of existing data to examine outcomes for carers alongside inputs from AN, whilst also exploring the perceived systemic impact of specialist nursing support for carers. The second purpose is to test the feasibility of collecting outcomes and costs data and then to undertake exploratory cost-effectiveness analysis comparing the outcomes and costs of specialist dementia nursing against ‘usual care’, which may include other forms of carer support services.

Health need: The average age of carers, their poor health, and the continuing impact that caring has on their physical and emotional health over time, make them a key group for support for health and social care services. The carers of people with dementia are more likely to be at a disadvantage in all respects than similar carers supporting people without dementia.

Expressed need: Exploring how specialist community nursing services can support carers has the potential to reduce financial costs for health and social care services and, more importantly, social, health and financial costs for carers themselves. It also fits closely with current policy preoccupations, not only in relation to dementia and carers, *per se*, but also in relation to the role of specialist, community-based nurses in supporting the health and well-being of adult carers[12]. *Compassion in Practice*[13] among other issues, outlines clearly the need for carers and those they support to receive help from community-based practitioners who are experienced and knowledgeable, for the improved use of specialist roles, and for greater harnessing of expertise to provide good quality support. All these, and many other issues outlined in this policy document, have clear relevance to the provision of specialist dementia nursing.

Sustained interest: Without carers, the UK health and social care system would be unable to cope with the additional demands placed on it; finding effective and efficient ways of supporting them to continue caring, if this is what they and the person they care for want, is thus of key importance in a country dealing with an ageing population. Yet, despite carers' potential vulnerability, and repeated policy focus on the need to support them, we seem to be little nearer delivering adequate support than we were when the first national survey of carers was carried out in 1985. Evidence of the effectiveness of specific 'carer interventions' is poor, but we do know that mainstream services for the people carers support also help carers themselves[14,15]. However, the most recent, nationally representative survey showed that just 11% of the people being supported by carers had a visit from a paid home help or care worker at least once a month. While in most cases carers said that visits from home carers were 'not needed', 25% of those not in contact did express some type of need. The proportions receiving visits from all other types of health or social care staff at least once a month were even smaller, and with similar levels of expressed need for most[16].

Generate new knowledge: High quality evidence about *how* to provide carer-specific support that improves outcomes at reasonable cost remains patchy and this is even more the case for carers of people with dementia. This group of carers tends to be older, mainly because partners are the main care providers and they are usually of a similar age as the person with dementia, with concomitant implications for their own health.

We currently know very little about the services available to carers of people with dementia across England, how carers engage with them, and whether they answer carers' needs. This study is a first step in understanding the national picture and preparing for future full-scale evaluation.

Aims and Objectives:

Aims:

1. Explore the processes, individual and system-wide impacts, and cost-effectiveness of specialist support for carers of people with dementia (using the largest such service - Admiral Nursing (AN) - as an exemplar).
2. Produce guidance to inform service delivery, organisation, practice, and commissioning of specialist support for such carers.

Objectives:

Using a mixed methods approach we will:

1. Carry out secondary analysis of an existing administrative database maintained by AN. We will use this to explore relationships between the characteristics of carers and people with dementia, AN service type and input, and outcomes.

2. Using qualitative methods (interviews, focus groups and cognitive interviewing) with carers, develop and test data collection methods that will allow us to carry out a subsequent cost effectiveness evaluation.
3. Conduct a survey of carers of people with dementia with and without access to AN services to explore the cost-effectiveness of AN services compared with usual care and determine the feasibility of a large scale evaluation.
4. Using qualitative methods (face to face interviews with health and social care stakeholders in four case sites – two with and two without AN services), explore the perceived system-wide impact of providing specialist support services for carers of people with dementia, as against usual care.
5. Implement new data collection methods in AN, to facilitate future evaluative research, and that could be used by other service providers.
6. Build on the findings of all elements of the project and work with key stakeholders to devise best evidence guidelines for service organisation and commissioning.

Research Plan

Design

In the absence of a secure evidence base for cost-effective interventions to provide support for carers of people with dementia, any high-quality evaluation will provide value. However, as the MRC Guidance on the evaluation of complex interventions advises, it is important not to rush to full-scale, summative evaluation, such as a randomised controlled trial, before developing understanding about the context within which interventions are delivered, their potential effects, and the feasibility of full-scale formal evaluation[17]. This is what we aim to do here by adopting a mixed methods approach, using secondary analysis of an existing administrative data set, with primary quantitative and qualitative data collection. This will allow us to make best use of existing and newly collected data to explore the potential effects and costs of specialist support for carers of people with dementia, while at the same time exploring the feasibility of formal evaluation in subsequent research. The work will address two major uncertainties identified in the Bunn et al. review[8] (table 1).

Table 1: Ways in which proposed research will address current uncertainties about AN services

Area of uncertainty identified by Bunn et al.[8]	Proposed work to address this uncertainly
Limited quantitative evidence on effectiveness, costs and cost-effectiveness of AN services	1. Secondary analysis of AN dataset to identify preliminary evidence on effectiveness (outcomes) of AN services (WP1). 2. Survey of carers using AN services and carers in similar areas without AN services to generate preliminary evidence on the effectiveness and costs of AN services (WP3).
Understanding of the relationship of AN to other health and social care services	3. Analysis of AN database to describe any (other) service support begun or discontinued after input from AN service (WP1). 4. Analysis of all service receipt by carers using AN services and by carers in similar areas without AN services, using statistical methods to control for possible confounding variables (WP3). 5. In-depth exploration, in four case study areas, with health and social care commissioners and service providers of the impact of specialist dementia services , including AN, on perceived impact on other health and social care services.

Work package 1: Secondary analysis of AN’s administrative data set

This work package will prepare the AN data set for research purposes and then carry out a range of analyses to explore the links between carer characteristics, the characteristics of the person with dementia, AN input and outcomes over time (objective 1).

The data set

AN has maintained a database of its activities with individual carers since 2005. Data on carers' personal characteristics, support needs, burden and physical and mental health, some details of the person being cared for and on services provided are collected by AN when they carry out their first assessment of carers' needs and entered in the data record. Data on variables such as needs, burden and health, as well as AN input are also collected at follow-up, allowing the exploration of outcomes over time. Needs assessment is carried out using AN's own tool, with standard coding.

The database currently includes 20,500 records in an Excel data set. The database includes both 'primary' carers and other family members defined as secondary carers, and cases that are now closed. It also includes records that log follow-up data for primary carers. In total, there are data for 1360 carers whose needs were assessed at both baseline and at least one follow-up point.

For a small number of carers, the data set also includes standardised outcome measures, of which the Zarit Burden Inventory is the one most often completed. In September 2014, around 3 per cent of open cases had a completed Burden Inventory in their record.

In September 2014, the database recorded 3373 open cases and 198 carers waiting for assessment.

Preparation of data for analysis

AN will provide a cleaned and anonymised data set containing records of carers who have used the service since 2005. However, as would be the case with any administrative data set, various issues need to be addressed before we can export the data and start analysis for research purposes. Two of these tasks will be carried out by AN before the data set is received at York and two carried out by the York research team.

We will need to:

1. Create flat structures for all the data, to allow linking across individual records Currently, data for each question in the needs assessment tool and the standardised outcome measures is entered on a separate row in the Excel spreadsheet. For example, the answers to questions 1 to 22 for the first carer who completed the Zarit Burden Inventory appear in the first 22 rows of the relevant sheet in the Excel spreadsheet. These data need to be converted into a flat structure (with all 22 answers in a single row) to allow us easily and securely to link the answers to the rest of record for that carer. AN will carry out this work.

2. Link baseline and follow-up (outcome) records for individual carers
   Each carer has a unique identifier, but follow-up data is recorded in a separate file from baseline data. We will therefore need to use the identifier to create single records for those carers where follow-up data is available. AN will carry out this work.
3. Devise a coding framework for data that is currently entered as text
   Much of the data in the AN data set is recorded as text. In order to carry out our planned analysis we need to create numerical (categorical) data from the text. We will do this in the same way we would if we were coding material from open-ended questions in a structured questionnaire. We will take a systematic sample of records, examine the text for commonalities and differences in the material for each 'question', and then devise and pilot a coding framework. Once the coding framework is finalised we will then code the textual material, thereby creating the categorical variables. Around 30 data fields in each carer record will require coding in this way. The York team will carry out this work.
4. Create variables to summarise the type of AN service received.
   We will create descriptive variables for the current AN services, using another AN data set that logs service details, including team composition and size, geographical area covered, referral processes, funding source and staff complement. Once created, we will add these variables to the individual carer records so that we can explore relationships between service characteristics and outcomes. The York team will carry out this work.

Analysis

We will make best possible use of this unique data set, first by using it to provide a detailed picture of the carers who have used AN services over time and how the carers vary, if at all, over time and by type of service.

Secondly, using those records where needs assessment has been carried out at more than one point, we will explore how AN service type, input and service users' characteristics (including the characteristics of the person with dementia) and needs affect outcomes (objective 1). We will do this by carrying carry out a range of uni-, bi- and multi-variate (regression) analyses, and establish the links between type and intensity of AN input, service user characteristics and needs, and outcomes. The initial uni- and bivariate analysis will explore patterns of change in outcomes, create change variables and identify service types. We will then use generalised regression and multi-level approaches to explore the unique and inter-related contributions of carer characteristics, service input and team types to outcomes.

Thirdly, individual AN services have changed over time – in their characteristics and functions, and since 2005, some have ceased to operate while others have started up. We cannot, therefore, use the data simply to 'describe' AN services. However, we can and will use the data to analyse what type of work was done with which types of carers, and use this to develop a model of the AN service ‘offer’. Given the longitudinal nature of the dataset, we can also track how, if at all, this offer has changed over time.

In writing up the analyses we will also bear in mind changes to the wider health and social care landscape since 2005 that may have affected the AN service ‘offer’.
All analyses will be carried out by the York team.

Work package 2: Develop and test data collection methods for survey and new data set

This work package will establish a data collection framework and processes for the survey in the final stages of our proposed work (objective 2).

There are two elements to the package. First, we need to establish what outcomes are important to carers in terms of their actual or anticipated use of specialist nursing support. Secondly, we need to identify ways of measuring those outcomes, in a robust way that is acceptable to and feasible for carers, for both our survey in work package (WP) 3 and use in service settings (WP 5). The in-depth exploration of the acceptability and feasibility of the framework and processes is an essential element of this work package, given the acknowledged challenges of evaluative research in dementia care.

Sample

We will identify two areas with an AN service and two areas without, and recruit seven or eight carers in each. AN will help us to identify carers in the AN service areas and the *Life Story Network* (through *TIDE: together in dementia everyday*) will help us to identify carers in the other two areas. We will aim for a total sample of around 30 carers, and will recruit people from a wide range of characteristics and circumstances.

Carers of people with dementia, by definition, find it difficult to free up time from their daily lives so we intend to recruit from four areas within easy travelling distance of York so that those who wish to participate in a group will be able to do so. We will also offer carers the option of an individual interview by telephone, or in their home or somewhere else to suit them. We will pay for the costs of substitute support for the person with dementia where this would help the carer to participate.

Methods

Developing the survey

We will talk to carers twice, using focus groups or, where requested, individual interviews.

At the first contact, we will use in-depth, qualitative methods to explore with carers the outcomes they would like to experience if receiving support from specialist dementia services focussed on carers. For those who live in areas without AN services, we will first describe the support they might get from such a service so that they can focus their responses on this type of service.

At the end of each group or interview, we will feed back the learning from the discussion and work with the carers to finalise the outcomes they would like us to take forward to the next stage of work. While we will record the groups and interviews (with carers' permission) we will not fully transcribe them. After the interviews, we will review the recordings, first to ensure that we did not miss any outcomes in the summing up and, secondly, to carry out a brief analysis of the material, under each of the outcomes identified. We will use the Framework principles of case and theme-based analysis, data reduction through summarisation and synthesis[18] to do this.

We will then identify robust, standardised measures that are available to assess the main outcomes that carers have identified. In doing this, we will be guided by the work that INTERDEM has done to identify good quality outcome measures in dementia care[19]. It is, of course, possible that there will be no measures for some of the outcomes carers want to achieve. In this case, we will develop simple questions for our survey to explore these questions.

The questionnaire has a dual purpose: first, to collect data on carers of people with dementia in areas with and without AN for WP 3 (see below) and secondly, to provide the basis for a draft data collection framework for AN to use routinely (see WP 5). Our survey questionnaire will include:

- Questions on the demographic and socioeconomic characteristics of the carer and of the person with dementia (e.g. age, gender, ethnicity, education and household resource level).
- Instruments that measure the outcomes important to carers. As discussed above, the specific questions and instruments will depend on findings from the focus groups and individual interviews. They might, for example, include a measure of burden (for example the Zarit Burden Inventory), a measure of

health-related quality of life (HRQoL) (for example, the EQ-5D), and a measure of subjective wellbeing[20].

- Questions on the time and resource use associated with caring, namely unpaid (informal) care time, out-of-pocket costs, health (e.g. hospital appointments, GP appointments) and social care (e.g. home care) and non-statutory sector (e.g. volunteer befriending service) resources. These will also include questions on other specialist dementia services accessed by the carer. The questions on resource use will be based on another questionnaire developed by the current team for an ongoing NIHR HS&DR funded project (the MORE project[21]).

We will then carry out cognitive interviews with our carers. These will explore their understanding of the questionnaire and its acceptability to them. We will also talk to them about the feasibility of carers' completing a questionnaire of this type on-line and in hard copy. We will also discuss with them the pros and cons of self-completion vs face-to-face or telephone interviews, as requested by the Commissioning Board.

We will test the administration of the survey, both electronically and in hard copy, with a small number (20) of carers who have not been involved with the earlier work. As before, AN and the *Life Story Network* will identify carers for this stage.

The survey will be developed within, and administered using *Qualtrics* (http://www.qualtrics.com). This is sophisticated, internet-based survey software that allows us to produce high-quality on-line questionnaires.

Work package 3. **Survey and analysis of outcomes and cost-effectiveness**

The key aims of WP 3 are:

(i) to understand the characteristics of carers, the people with dementia that they support, and their outcomes and costs with and without AN services.
(ii) to explore the cost-effectiveness of AN by comparing relevant carer outcome and costs in areas with and without AN services.
(iii) to evaluate the feasibility of recruiting carers and collecting their outcomes via online and postal questionnaires in future research

These aims address objective 3.

Rationale for our chosen design

Our aim in this section of the proposed work is to compare carers of people with dementia who use AN services with those who do not (who receive 'usual care") both to judge the likely effect of AN services on carers' outcomes and to assess the costs of AN services against any benefits that may be identified.

Definition of Admiral Nursing vs 'usual care'

We wish to compare the costs and effects of AN with those of usual care. AN is the only specialist nursing service for carers of people with dementia, so we can feel relatively sure that carers in non-AN areas will not be receiving any carer-focussed, dementia-specific services. Other services that both AN and non-AN carers may experience include visits from community-based mental health nurses, home care services and social work input. However, we would expect to see substantial heterogeneity, given the diversity of support services for people with dementia and their carers and the diversity of provision across the country. It is possible, that AN services may *substitute* for other forms of services that carers might otherwise have received. However, we think it is more likely, given the objectives of AN services, that they will enhance carers' access to other services, via signposting and direct liaison.

The survey is the first step in describing the services providing support for carers as we will ask respondents about the services that they know are available in their area, and those they use. It will thus help us understand whether AN enhances access to or acts as a substitute for other services. Our analysis will be strengthened by also surveying a small number of carers who live in AN areas but do not use AN services.

Choice of design

Our chosen design to achieve our main aim is cross-sectional. We have chosen this approach because carers of people with dementia are a precious research resource and longitudinal data collection would impose additional burdens on them and, in all likelihood, reduce response rates over time. However, our design of the sampling and analysis strategies will allow us to carry out robust cross-sectional comparison between those who do and those who do not use AN services.

First, the sample selection processes reduce heterogeneity, both within the AN services being evaluated and between carers in areas with and without AN services.

Secondly, our analytical plan allows us to control for any differences that remain between carers with and without AN services, once data have been collected. As well as regression analysis, we propose to test and further develop an innovative method developed by Forder et al[22] to conduct a cost-effectiveness analysis using survey data. Forder et al used survey data to relate the receipt of home care services to wellbeing (using the Adult Social Care Outcomes Framework – ASCOT) using an instrumental variable approach to minimise the risk of selection bias.

Choice of sampling frame

We will generate simple, two stage cluster samples of local authority areas that have 'standard' AN services and broadly similar (matched) local authority areas without AN services. Proportionate random sampling of current users of AN services in the former and of carers in contact with the *Life Story Network* in the latter will generate the respondents for the survey.

'Standard' model of AN services

As outlined in the introduction, AN services vary in their composition, remit, funding models, case mix and other key characteristics. For the purposes of this work package, however, we need to compare outcomes from services that are 'typical' of the majority. We will therefore select areas with AN services that deliver a 'standard' model which we define as:

- based in the community (rather than in a long-term care setting)
- providing support mainly to carers where the person they support still lives in a private household
- funded to provide support to any carer (so excluding third sector funded services that provide support only to a sub-group of carers).

Matched areas

We will define 'broadly similar' areas in terms of statistical neighbourhood, as defined by CIPFA's statistical model

(http://www.cipfastats.net/default_view.asp?content_ref=18003). Statistical neighbourhood is used by local authorities themselves, and across government, to allow comparisons between authorities that are similar in terms of population size and characteristics, such as age distribution, deprivation and ethnicity. For example, the Department of Health has developed an interactive adult social care efficiency tool (https://www.gov.uk/government/publications/adult-social-care-efficiency-tool) that compares local authorities' performance on service provision to and expenditure on older people and people with a learning disability. Statistical neighbours will also be used to select comparison areas in work package 4.

Sample size

Sample size calculation for cross-sectional surveys of populations is simple when the sole aim of the survey is to describe the population within given statistical tolerances. Similarly, sample size calculation is relatively simple when the sole aim is to compare outcomes between equivalent groups which vary only in their receipt of an intervention. However, this latter does also require prior knowledge about or indication of what size of effect one might be expecting, or what average level of a chosen outcome one might expect to see in the selected population prior to intervention.

In our survey, we wish both to describe *and* to draw inferences about what effect using AN services might have on carers of people with dementia. While our sampling strategy (see above) will reduce some of the likely variation between users and non-users of AN services, we also need to control for any other differences between them that become evident after collecting data. This is so that we can feel confident that we are seeing the effect (if any) of AN services on measured outcomes, and not the effect of some other differences between carers.

Further, it is challenging to find any up-to-date, population-based evidence about the average levels of (say) the quality of life of carers of people with dementia, or UK-based comparative studies that might hint at possible effect sizes from similar types of intervention.

Given these challenges we have taken a pragmatic approach to sample size calculation, using three different approaches. The first was a simple, population survey sample calculation. The second was a sample calculation for comparative research, using the effect sizes found in a randomised controlled trial of community occupational therapy in the Netherlands[23] that aimed to help carers' use 'effective supervision, problem solving, and coping strategies' with a view to sustain both their own and the person with dementia's 'autonomy and social participation' (p. 1003). This intervention also included similar input for the person with dementia and found very substantial differences on a range of outcomes at three month follow-up. The final stage was to assess how many independent variables could be included in multivariate analysis, based on the calculated sample sizes. The results of these calculations are in the table below.

	Assumptions	**Assumed response rate**	**Total achieved sample size required and original sample size to ensure this**	**N of independent variables in regression using more and less conservative inflators (10 observations or 5 observations per variable)**
Population survey sample calculation	66% of people with dementia live in the community with support of a carer (population size c. 528000) 30 clusters Design effect of 1 (random sampling)	60%	384 (640)	Achieved sample size would allow for 38 independent variables using conservative ratio, 76 using less conservative ratio.
Comparative research sample calculation	Mean difference of -5.0 points on GHQ, with 5% confidence level and 80% power	60%	16 (26)	Achieved sample size would allow one independent variable using conservative ratio and three using less conservative ratio.

A pragmatic decision about an achievable sample size, within reasonable resource use, clearly takes us to a decision somewhere between these two figures. Assuming that we would need to control for up to 20 independent variables in regression analysis, an achieved sample of 320 would be needed to detect differences of the size observed in the Graff et al study[23].

We have assumed that the response rate in non-AN areas may be lower than that for AN users (say, 50%, rather than the 60% we have achieved in a recent survey of carers in another NIHR-funded project). Taken together, to achieve 160 in each group, we would need to sample around 270 carers from AN services and 320 in non-AN areas – a total of 590.

The average caseload per AN team is 35 carers (personal communication with the AN service). We therefore need to sample at least 13 teams to achieve our required sample (again, assuming a 60% response rate for this group). However, given the clustered nature of our sampling approach, we will increase this to 15 teams to give us the recommended minimum of 30 clusters (15 AN areas and 15 matched non-AN areas) for this type of survey design.

AN teams will identify carers who are currently using the service in the selected AN areas and the *Life Story Network* network will identify carers in our chosen non-AN areas.

Where the number of cases per team or per network is greater than needed for sampling, we will use proportionate random sampling to generate the required numbers.

Methods

Survey

In our 15 AN areas we will ask the AN services to identify carers of people on their current case load and to facilitate distribution of the questionnaire developed in WP 2. We will also work with *Life Story Network* to recruit the required numbers of carers of people with dementia in our matched non-AN areas. In both cases, we will offer the option of electronic and paper-based delivery, depending on individual preferences.

For paper-based questionnaires, we will include a leaflet explaining our study and its objectives, the questionnaire, a pre-paid envelope for return directly to the research team, and a question asking carers to consent to be contacted in a future study, and for their contact details. For questionnaires delivered electronically, we will attach the same leaflet explaining the study to an email which will also provide a unique electronic link to the survey.

We will send carers a voucher for £10 on receipt of their completed questionnaire, to thank them for taking the time and effort to answer the questions and contribute to our research.

Data entry

Data gathered via Qualtrics will be exported as an Excel spreadsheet, which can then be exported to statistical software (Stata ®) for analysis. Data returned via paper-based questionnaires will be checked for quality and then entered manually.

Analysis

We will conduct a number of descriptive and regression analyses that will enable us to understand the characteristics of carers and the person they support and how these relate to their outcomes and costs, with and without AN services. We will also use data on responses to the survey to assess the feasibility for future research of collecting data on carers and the people with dementia they care for via online and postal questionnaires.

The analysis is plan is designed to include the exploration of outcomes, cost-effectiveness analysis and methodological learning.

Describing outcomes

The first stage will describe the characteristics of carers and explore their relationship to outcomes. Uni- and bi-variate analyses will explore carers' demographic and socio-economic characteristics, health, carer specific outcomes (e.g. level of burden, hours of care per week), resource use and costs (carer-specific services the carers are aware of and use, and other health and social care services or voluntary support received).

This preliminary work will also allow us to compare the response rates and overall characteristics of the AN service users and carers from the non-AN areas. This will allow us to specify potential confounding variables for the subsequent multivariate analysis, as well as to establish the representativeness of carers who have completed the survey.

In the second stage of analysis, we will cost the health and social care services used by carers using national unit costs where available[24] or the local unit costs of services otherwise. We will conduct descriptive analysis of the resource use and costs used by the carers and evaluate the relationship between carers' characteristics, characteristics of the person with dementia, outcomes and costs. The relationship between costs to the health and social care sector by type of area (with and without AN), controlling for characteristics of the carer and person with dementia, is of particular interest since it will indicate whether the AN service can generate savings in the health and social care sector by providing support to carers.

Building on stages 1 and 2, we will then carry out multivariate analyses using regression techniques to inform a cost-effectiveness analysis that will establish the relationships between the carers' characteristics, costs and outcomes, all other things being equal.

Cost-effectiveness analysis

The cost-effectiveness analysis will aim to evaluate the costs and effects associated with AN compared to usual care for carers, the NHS, social services and voluntary sector services, and including out of pocket expenses. This will be the first attempt, to our knowledge, to explore whether AN is good value for money and to assess the costs and benefits associated with the alternative intervention, that is 'usual care'.

We will analyse survey data in a non-experimental setting and apply state of the art econometric methods to control for confounders, where possible, and to value informal care.

In the primary analysis, the cost-effectiveness analysis will follow the reference case by the National Institute for Health and Care Excellence (NICE) for health care interventions from the NHS and Personal Social Services (PSS) perspective[25]. In a secondary analysis, we will take a societal perspective and follow the NICE reference case for social care interventions[26].

> *Primary analysis: cost-effectiveness analysis under the NHS and PSS perspective.*
> We will compare the costs falling on the NHS and PSS budgets and the health-related quality of life (HRQoL) of carers who use AN services in areas with AN with those of carers who live in areas without AN. The costs and HRQoL of carers will be reported directly by the carers in the survey. The costs falling on the NHS and PSS budgets include: hospital appointments, primary care appointments (GP, nurse, etc.), home care funded by the local authority and the AN service itself. Resource use will be costed using published, national average unit costs[24] and NHS reference costs[25], where available, so that the cost analysis is as generalisable across England as is possible.
>
> *Secondary analysis: cost-consequence analysis under a societal perspective.*
> We will compare the costs falling on the NHS and PSS budgets, the voluntary sector, out-of-pocket costs for carers, other informal (unpaid) care costs and a range of carer outcomes (as measured by the instruments selected in WP2) in carers using AN services and carers without access to AN services.

Detailed description of how we will address the issues of comparability and unknown confounders
First, we will assess comparability (also known as overlap) with: normalised differences (a normalised difference above 0.25 will be taken as lack of overlap); histograms; quantile-quantile plots and kernel plot of the propensity score. We will analyse the costs and benefits of AN services versus non-AN with multivariate regression if comparability is high. Secondly, if comparability is a problem, we will conduct propensity score matching to ensure the costs and benefits of AN carers are compared against similar carers in non-AN areas. The success of propensity score matching will be assessed with a kernel plot of the distribution of propensity scores. Thirdly, if comparability has not been achieved, we will consider trimming the sample. Trimming the sample limits the number of variables that we will be able to include in the multivariate regression (since it decreases the degrees of freedom). Fourthly, we will explore the applicability of the instrumental variable approach

proposed by Forder et al. This relies on finding a suitable instrument. Forder et al used the local authority as an instrument. We do not currently know whether the local authority or another variable will be a suitable instrument, as part of the survey's purpose is to inform this decision.

Methodological learning

As discussed above, given the non-randomised, cross-sectional nature of the data collection process, quantifying an association between outcomes and the availability of AN services requires us to be sure that carers responding to the survey in areas with and without AN services are comparable in observed factors that might affect outcomes (i.e. confounders). Potential confounders include the education level of the carer, the level of severity of dementia experienced by the care recipient, and other services received by the carer and/or the person with dementia.

As described above, we will control for confounders and hence minimise bias within our regression analyses. However, we will also explore other methodological approaches to dealing with confounding that will help to inform future evaluative research in this challenging area. These will include:

- Multivariate analysis using pre- and post- propensity score matching, Propensity score matching is a statistical technique that helps generate comparable groups of individuals with and without the intervention of interest[28]. The propensity score is the probability of receiving the intervention based on the individuals' (in this case, carers') characteristics. Propensity score matching selects individuals in the intervention (AN service user) and in the control group (carers in areas without AN) that are similar in the characteristics included in the estimation of the propensity score. Use of this approach will depend on the proportion of completed questionnaires as it requires a relatively large dataset.
- Exploration of an innovative method proposed by Forder et al[22] to conduct a cost-effectiveness analysis using survey data. Forder et al used survey data to relate the receipt of home care services to wellbeing (measured using the Adult Social Care Outcomes Framework – ASCOT). Their approach assumed that an additional hour of home care was associated with an increase in wellbeing. In this study, there was a risk of selection bias and confounding because individuals with greater needs were likely to receive more hours of home care but also have worse wellbeing (due to those greater needs). Forder et al minimised the risk of selection bias using an instrumental variable approach. The instrument was the local authority, since different local authorities have different policies for the number of hours offered given the level of need and these policies are unrelated to carer outcomes. This approach, although potentially promising for research in dementia care,

requires further development before it can be used widely in health and social care research. Availability of the data from our survey will allow us to explore further the potential of this approach in the area of service evaluation, where using ‘gold standard’ designs such a randomised controlled trials can be challenging.

Work package 4: Understand the wider impact of specialist support for carers of people with dementia

Specialist dementia services’ effects may extend beyond individual outcomes and resource use, having effects also at a system level. For example, if services enable carers to care for longer, or help them to remain healthy they may reduce costs to both health and social care systems. This work package will explore with health and social care stakeholders what they perceive to be the system-wide effects of supporting carers of people with dementia, with a specific emphasis on specialist nursing support of the type AN provides.

Sample

We will select two areas with AN services that deliver a ‘standard’ model, defined in the same way as for WP 3, that is they are:

- based in the community (rather than in a long-term care setting)
- providing support mainly to carers where the person they support still lives in a private household
- funded to provide support to any carer (so excluding third sector funded services that provide support only to a sub-group of carers).

We will then select two areas that do not have AN services but that are in broadly similar areas to the AN services. We anticipate selecting areas that were also selected for WP 3, allowing us to triangulate our qualitative and quantitative findings in these areas (so treating them as case studies).

Within each area, we will identify the key health and social care stakeholders in relation to dementia care and support for carers. This will include both statutory and third sector (for example, senior managers of local Age UK or Carers UK) stakeholders. We will start with the main health service and the main social care commissioner for dementia services in each area and then use snowballing techniques to identify other stakeholders.

We will grow the sample until we are learning nothing new (i.e. we achieve saturation of the data). In line with our previous research exploring health and social care for people with long-term conditions, we would expect to identify between 12 and 15 key stakeholders in each area to achieve saturation.

Methods

We will carry out in-depth, semi-structured interviews with stakeholders which will explore the perceived system-wide impact of carer services such as AN, as against ‘usual care’ (objective 4). The interview aide memoire will be developed once the project starts but we would expect it to cover at least the following topics:

- current provision and cost of support for carers of people with dementia,
- perceived impact of this support (or its lack) on other health and social care services,
- the balance between the costs and benefits of supporting carers,
- and future plans for (further) developing support for carers of people with dementia.

In the AN areas, we will also cover topics specific to AN, such as commissioning arrangements and intentions.

We will also use this stage to explore the feasibility of implementing routine collection of outcome and resource use data in whatever (other) services the areas provide for carers of people with dementia.

Analysis

We will record and transcribe the interviews and analyse them using the Framework Approach[18].

Work package 5: Implement a new data collection system for AN and promote it to other dementia service providers.

Using the data collection framework established in WP 2, we will work with AN to develop and test the new data collection framework that will provide data required for future evaluative research while also meeting their administrative needs. This will build on the work in prior stages to understand the feasibility for dementia service providers, and acceptability to carers, of using a range of validated outcome measures as part of routine data collection.

Following the general shape of the survey questionnaire, we expect the framework broadly to include socio-economic data, quality of life measures (both generic and carer-specific), informal carer time, and health and social care resource use, as well as administrative data that describes AN activity and inputs with individual carers. We will pilot the new framework with one AN team to test its feasibility in the field.

Work package 6: Develop best evidence guidance for service commissioning and delivery of support for carers of people with dementia

The final stage of our project will be a stakeholder workshop that will present the findings of all elements of our research. We will work with stakeholders during a full-day event to draft a statement about current evidence for specialist support for carers of people with dementia, how different models of support might influence outcomes, and how to collect data at a local level so that it informs both service development and evaluation.

We will invite a range of stakeholders including people with dementia and carers, decision-makers from health and social care commissioning and providing organisations (including the third sector), and local and national policy makers.

After the workshop, the draft guidelines will be circulated to participants and other stakeholders for comment before they are finalised and disseminated as a project output (see below).

Dissemination and outputs

In addition to intermediate and final reports for NIHR, we plan a range of dissemination activities targeted on those who deliver, organise and use dementia care services.

Best evidence guidelines**: w**orking with partners and other stakeholders, key findings from the project will be used to formulate a statement about current evidence for specialist support for carers of people with dementia and how different support models may influence outcomes. This work will take place at an invitation workshop in York towards the end of the project. We will then produce best evidence guidelines for developing and commissioning specialist support for people with dementia and their carers.

We will advertise and promote these guidelines to health, social care and other dementia care providers and via our partner organisations and other identified stakeholders. We may develop very short ‘key point cards’ or ‘key ring flash cards’ in place of Research Work summaries (see below) as outputs from these projects, if our partners and other research users feel that these will have more impact on policy and practice.

A project webpage will be established on the SPRU website at the outset of the project. This will describe the planned work and will be updated throughout as outputs are produced. All project webpages remain permanently accessible via the SPRU website, thus ensuring legacy for the work. Tweets and blog posts will be used throughout the project to highlight progress and, in due course, findings and outputs.

Research Works for the research findings. These are four page ‘glossy’ summaries of research findings written in plain language. They are disseminated in hard copy format to targeted groups of health service and social care policy makers, providers and commissioners, other dementia care providers, relevant third sector organisations and members of the public. They are also downloadable from the project web pages.

Podcasts to communicate findings relevant to policy and practice will be placed on the project’s web pages.

Promotion of use of the data framework for other types of dementia service providers who support carers

The survey questionnaire will be edited to provide a stand-alone data framework that other providers of services that aim to support the carers of people with dementia could use to evaluate their own work. This framework will be available via the project web page on the SPRU web site and will be free to download for non-commercial purposes for use in publicly funded services. We will promote the data framework via our partners and the stakeholders involved in the best evidence guideline work, via our existing networks of health and social care providers and via the project’s Tweet and blog posts.

As well as these service- and user-facing outputs, three academic papers will report the secondary data analysis, the cost-effectiveness work, and the perceived systemic impact of support services.

Plan of investigation and timetable

Two months before project starts: obtain any necessary approvals from Health Research Authority in relation to Section 251 of the NHS Act 2006 (see section on ethical approval)

One month before project starts: AN database manager prepares data set for transfer to research team, including anonymisation.

Months 1-6

WP 1. Research team receives AN data set and devises coding frame for textual data. Coding of textual data in 20,500 records. Export of coded data set into SPSS.

Exploratory univariate analyses, followed by definitive bi- and multivariate analyses. Analysis of outcomes data for the sub-set of cases that allow this.

WP 2. Ethical approvals applied for and obtained for qualitative and quantitative (survey) research with carers.

Two AN and two similar, non-AN, areas selected for qualitative work exploring outcomes with carers. Research team works with AN and the *Life Story Network* to identify and recruit carers in these areas.

Months 6-11

WP 2. First rounds of individual interviews and focus groups. Rapid analysis of material to aid development of data framework for survey. Review of high-quality instruments to measure outcomes important to carers and, where these do not exist, development of relevant questions for inclusion in survey.

Full development of data framework for the survey and subsequent data collection instrument for AN and other service providers. Design of survey questionnaire.

Cognitive testing and piloting with carers of survey questionnaire for WP 3. Survey questionnaire finalised.

Months 12-15

WP 3. Identify with AN the 15 teams for WP 3. Choose 15 matched local authority areas. Research team prepares survey for distribution via *Qualtrics* and/or by post. AN notifies service users of survey and prepares to distribute the link for the electronic survey and/or hard copy versions. *Life Story Network* identifies carers in matched non-AN areas and prepares to distribute the link and/or hard copy versions.

Survey launched with four-week initial return period. First reminders distributed at the end of this period. Second survey reminder distributed six weeks after survey distributed.

WP 4. Commence interviews with health and social care stakeholders in four selected areas.

Months 16 to 19

WP 3. Survey data downloaded, analysis carried out and written up.

WP 4. Interviews with health and social care commissioners completed, data analysed and written up.

WP 5. Work with one AN team to implement and test a new data collection system, based on survey questionnaire.

Months 19 and 20

WP 6. Preparation for stakeholder workshop. Stakeholder workshop and drafting of guideline. Post-workshop consultation starts with workshop participants and other stakeholders.

Month 21

Final guideline written. All analyses completed. Draft final report written and submitted

Project Management

Overall project management will be the responsibility of Professor Parker, who will ensure delivery of the work to time and to budget. Each work package will also have a lead researcher, who will be responsible for delivery of the described work in that package.

For WP1 the lead researcher will be Professor Parker, who will also supervise the work of the grade 6 researcher on this WP. For WPs 2, 4, 5 and 6 the lead researcher will be Ms Gridley. For WP 3, the lead researcher will be Ms Faria. Professor Parker will supervise and mentor Ms Gridley and Professor van Den Berg and Ms Weatherly will supervise and mentor Ms Faria.

There will be monthly meetings of the York team throughout the project to review progress and plan next steps. Ms Maio will join these meetings via telephone conferencing and the *Life Story Network* will similarly join when required.

A project steering group, with an independent chair, will be established, as required by NIHR. Professor Brendan McCormack, of Queen Margaret University, Edinburgh has agreed to be the chair. Dr Harrison-Dening from AN and Ms Jean Tottie from *Life Story Network* will also attend the steering group in an *ex officio* capacity, to ensure proper lines of accountability for their organisations' involvement in the project, but all other members will be independent of the research team. Two carers of people with dementia have already agreed to be members of the group. We will progress with recruitment of other stakeholders in due course; these will include health and social care commissioners and service providers and third sector representatives, as well as organisations that represent the views of people with dementia. The steering group will meet three times over the 21 months of the project; the first meeting will be in month 3.

This is a bid from a single academic institution and builds on a growing relationship between the Social Policy Research Unit and the Centre for Health Economics. Our current work on the NIHR funded MORE project (evaluation of different models of reablement) is progressing well and demonstrates our ability to work creatively together.

Approval by Ethics Committee

Secondary analysis of administrative data sets does not usually raise ethical issues, unless the analysis will involve personally identifiable data. We outline above the processes we will use to anonymise the AN data. We have completed the Health Research Authority (HRA) Confidentiality Advisory Group pre-application tool and taken further advice from them about whether our use of the Admiral Nursing database requires HRA approval. The advice we have been given suggests that we do not require approval, but we will confirm this finally, and in writing, if the project is funded.

Interviews with carers of people with dementia about the outcomes they would like to see from specialist support raise ethical issues if they prompt carers to reflect negatively on their situation. We will design and carry out our in-depth interviews sensitively and based on our experience in this field, but we cannot guarantee that no carer will become distressed. However, we have a range of provisions in place to deal with this possibility. Kate Gridley, who will be leading the qualitative work with carers, is an experienced researcher in the dementia field and has received specialist training for working with people with dementia and their carers. SPRU has written guidelines about dealing with distress in interview situations, which includes asking people if they would like to be put in touch with sources of support. Further, at the end of the interviews, all carers will be given a resource pack that contains information and contact details about local and national agencies and groups able to provide advice and support. This will include details about the AN telephone helpline for carers in areas without AN services.

All carers will receive information about the project before they agree to participate and give informed consent if they do. This will include information about our responsibilities as researchers if we suspect that the carer or someone close to them is at risk of harm. SPRU has written guidelines that all researchers follow, about how such suspicions should be raised with people being interviewed and what should be done next.

It is also possible that the survey will prompt negative reflections or distress, although the careful preparation of the survey via work with carers in WP 2 should minimise this possibility. However, as with interviews, we cannot guarantee that no individual carer will become distressed. Carers who receive the link to the survey or a postal version will also receive information about the purpose and content of the survey and the project overall. They will also receive information about sources of advice and support and details about how to contact the research team, if they wish to talk to someone about the project in person.

Although the carers we will identify for our qualitative and quantitative work will not be recruited via the health service or social services, nonetheless some will be recruited via AN services that are funded by the NHS or local authorities. We will therefore apply for ethical approval for the project via the HRA rather than the University of York ethical committee.

We do not believe that the interviews with health and social care stakeholders raise any particular ethical issues. We expect that all will be senior members of their organisation. We will, however, require ADASS approval to approach stakeholders from local authority social services departments and will do this at the beginning of the project.

Patient and Public Involvement

This application is based on a partnership between the research team and Dementia UK, a third sector organisation that campaigns for and supports people with dementia and their carers. Admiral Nursing is hosted within Dementia UK and has, for some time, wished to carry out research to explore the impact it has (or not) on the carers it works with. Discussions between the research team, AN and Dementia UK, to take this wish forward, thus form the basis of this proposal.

We have also consulted locally with people with dementia and carers as part of our White Rose (Universities of York, Sheffield and Leeds) collaboration on dementia, cognition and care, to establish a future research agenda driven by the concerns of people with dementia and carers about the care and support they receive. Specialist nursing support for carers (or, more accurately, its lack) was one of the main topics identified in this consultation.

We have worked with AN in preparing this outline proposal, and have shared the completed outline with two carer members of our White Rose consultation group, who have both also agreed to be on the project steering group.

TIDE (together in dementia everyday), which is currently hosted by the *Life Story Network*, will establish an advisory group of carers of people with dementia that will meet six monthly (in person or via telephone conferencing and the internet) to advise on the project proposal, progress and findings. The group facilitator, who was a carer for a person with dementia in the past, will be the link between this group and the project steering group, attending meetings of the latter to present the views of the carers' group. This arrangement allows carers to express their views (which may or may not be critical of the research) in a facilitated and supportive environment where they also talk to other carers. We have used this model of carer involvement in our current NIHR-funded project on Life Story Work in dementia care and have found it of great value. Carers have been empowered to be both critical and supportive of what we are trying to do and this, and their accounts of the lived experience of caring, have undoubtedly improved the project.

As with all SPRU-led projects, we will, if funded, also use our permanent consultation group of disabled people and carers to give critical oversight to our project, by also sharing the proposal, progress and findings with them throughout. We have already shared the outline proposal with this group who were very positive about the project and its aims.

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