“CARER SUPPORT IN HOSPITAL”
EVALUATION OF A PILOT SERVICE AT
ROYAL SUSSEX COUNTY HOSPITAL

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Most importantly, the study could not have taken place without the contribution of the carers themselves, who completed questionnaires that contributed to our understanding of the project’s impact on their wellbeing. In some cases, carers agreed to be interviewed too about their experience, and we acknowledge with gratitude how their perspectives have enabled us all to reach a much fuller understanding of the challenges they face and how services can make a difference.

Suzy Braye, Mick Finlay, Imogen Taylor: March 2011
“CARER SUPPORT IN HOSPITAL”: EVALUATION OF A PILOT SERVICE AT ROYAL SUSSEX COUNTY HOSPITAL - EXECUTIVE SUMMARY

1. Introduction

1.1 The project:
The project, funded by the South East Regional Improvement & Efficiency Partnership and by the DH South East Regional Office, ran for one year, January to December 2010. It aimed to provide information, needs assessment and support to carers of hospital in-patients, in order to enhance their involvement in discharge planning, and facilitate the transition to ongoing care arrangements.

1.2 The evaluation sought to:
(a) report on expectations of and satisfaction with the pilot project by policy formulators, managers and front-line staff;
(b) describe and analyse the processes and outcomes of support provided;
(c) assess whether the project met its objectives of increasing carers’ capacity, confidence and participation, and reducing hospital bed-days and readmissions;
(d) identify the views of carers on the support they experience through the project;
(e) identify impact on hospital discharge staff’s engagement with carers.

The methods included:
• Interviews with those responsible for the development, management and delivery of the project at two time points, to gauge expectations and satisfaction;
• Focus groups with hospital discharge staff at two time points, to identify changes in perception of carers as care partners;
• Completion by carers of a wellbeing assessment tool at referral and case closure;
• Analysis of carers’ assessment documentation;
• Comparison of the bed occupancy days of the cared-for person with the length of stay for all patients in the same health resource group;
• Semi-structured interviews with carers with experience of using the service’;
• Telephone follow-up by the care manager of a small sample of carers not formally assessed by the service.

2. Findings

2.1 Project overview:
(a) The pilot service had contact with 182 carers from January until mid-December 2010, with 122 carer’s assessment completed. The sample of carers who completed the carer’s assessment tended to be older adults, with an average age of 64.8 years and 40% of the group over the age of 70. Almost all were white British, and most were either the partners/spouse or the adult children of the cared-for person.
(b) Carers were providing a high degree of support, with 90% providing over 35 hours care per week. The cared-for person often had multiple health conditions and/or impairments, the most common being mobility issues, dementia and heart conditions, although there were many other conditions mentioned by carers.
(c) Comparison with national averages showed that there were significantly more patients in the pilot sample with shorter than expected stays in hospital (38) than with longer than expected stays (22).

2.2 **Carers’ wellbeing:**
(a) Comparison of carer wellbeing scores available for a sample of 32 carers showed a significant improvement in carers’ confidence and satisfaction with their role over the course of the project. In addition, the total wellbeing scale and the questions on carers’ own health showed improvements that approached significance.
(b) It is encouraging that carer’s wellbeing did not decline on any of the measures, and showed improvement on one crucial dimension, especially given many patients had conditions likely to deteriorate and potentially increase demands on carers.

2.3 **Carers’ perspectives - interviews with 20 carers:**
(a) Seven people seemed to accept their role as carers as natural, while five expressed a sense of frustration. Carers described a variety of negative effects, included fatigue, frustration, stress, health effects and depression. While ten carers felt confident they could continue in their role, eight expressed concern about their ability to continue.
(b) While seven carers found it difficult to remember exactly what the pilot service had done, a wide range of support was described in the interviews and had been valued. Most often mentioned were the provision of information and links between services, the reassurance that came there being someone to call if help was needed, help with financial issues, and referral to specific services.
(c) The care managers were described in very positive terms and the service as being helpful by almost all carers. Eighteen of 20 people felt positively about their contact, while two people felt negatively. One could not remember his contact; the other had services that did not work out, and would have liked more active follow-up.
(d) A number of services that had been arranged had either fallen through or had not been taken up. Reasons included that the cared-for person did not want the service, the service was unavailable, the cost was considered too much, and the service was not of suitable quality. Home care-workers were criticized by a number of carers. When services did not work out, carers often seemed to have given up on them and seemed reluctant to ask for help after contact with the pilot service had ended.
(e) Although many carers praised some hospital wards and some individual staff, thirteen recounted negative experiences in hospital. Complaints included that staff were too busy to communicate with or to care for the patient adequately.

2.4 **Stakeholders’ perspectives:**
(a) There was consensus amongst the key stakeholders that prior to the pilot service there had been insufficient focus on carers’ needs, and that attending to carers’ needs was in some respects difficult in the context of drivers for rapid discharge.
(b) The service was expected to make, and was thought to have made, a significant and important contribution to carers’ wellbeing and to appropriate hospital discharge through its dedicated focus on carers needs, assessment and support.
(b) The project made staff more aware of carers’ issues, particularly among hospital social workers and the integrated discharge team. Pressure of work had affected
how widely known it could become within the hospital environment as the educative function with staff had ceded to the higher priority work with individual carers.

(c) The project’s location within the hospital environment was important for systems knowledge, and for identification of hidden carers.

(d) A further positive was the ability of the care managers to work flexibly across hospital/community boundaries and to determine the length of their involvement, allowing continuity of relationship and support at a crucial time of transition.

(e) Challenges were experienced in setting up the project and embedding it within hospital systems.

(f) Community organisations representing carers’ voices became involved in the project, and considered they could have engaged further on plans prior to implementation.

2.5 **Hospital discharge staff perspectives:**

(a) Discharge coordinators considered that whilst their focus is primarily the discharge of the patient, they do undertake a considerable amount of work with carers, although their role here is often to advocate for the patient.

(b) There was little evidence that the project had made a difference to the work practices in hospital discharge but members of this team were very supportive and believed the role should continue.

3. **Conclusion and recommendations**

The pilot service is valued by key stakeholders and carers alike and the evaluation provides evidence of positive outcomes and successful working practices. The decision not to continue the service in its present form is clearly not linked to perceptions of its effectiveness. The following recommendations are designed to support further future work with carers in whatever context or organisational structure that takes place.

(a) In order to ensure that legal obligations under carers’ legislation are met and national policy goals supported, consideration should be given to how carers’ interests and contribution to timely discharge can be facilitated, and the lessons learned from this pilot project brought forward into new service structures.

(b) Further dedicated resource is likely to be helpful in supporting a focus on carers’ needs, whether this is provided through a dedicated service or through a higher profile for work with carers in other adult social care services.

(c) It is important that some services for carers are available within the hospital context.

(d) There should be proactive preparation at strategic and operational levels for the introduction of innovatory services in order to encourage ownership of ‘carers as care partners’ perspectives across complex organisational systems.

(e) Tools for tracking carers’ health and wellbeing should be built into assessment and reassessment schedules to facilitate building robust evidence on effectiveness.

(f) Hospital/community services boundaries must be flexible enough for carers to experience continuity of support.

(g) More robust care pathways/options at case closure are needed to ensure that carers are able to rely on ongoing, longer-term supports.

(h) Strong links with community organisations able to give voice to carers’ perspectives, and their early involvement in plans at both strategic and operational level, are vital.
“CARER SUPPORT IN HOSPITAL”: EVALUATION OF A PILOT SERVICE AT ROYAL SUSSEX COUNTY HOSPITAL

1. Introduction

This report presents the findings of an evaluation of the Carer Support in Hospital pilot project at the Royal Sussex County Hospital. The carer support pilot project ran for one year, between January and December 2010. Its aim, as identified in the project initiation document, was the provision of information, support and assessment to carers of inpatients at the hospital, in order to enhance their involvement in decisions, treatment and discharge planning for the person cared for, and to support them through the transition from hospital to ongoing care arrangements.

Through this intervention, the pilot project sought to increase:

- Carers’ ability to assume/continue a caring role;
- Carers’ confidence and participation in services;
- The utility of information and support in the hospital setting;
- The extent to which carers are seen as ‘expert care partners’ by hospital staff.

Equally, it sought to decrease:

- Hospital bed-days;
- Re-admissions following discharge;
- Long-term care admissions.

The project staffing comprised two full time care managers for carers, based and managed within the hospital social work team. Project management was provided by the Joint Commissioner for Carers and the General Manager (Hospitals) within adult social care at Brighton & Hove City Council. Funding for the pilot project and its evaluation was provided by the South East Regional Improvement & Efficiency Partnership and by the Department of Health South East Regional Office.

The Project Initiation Document\(^1\) described the scope of the project in the following way:

“The scope of the project covers services to carers, including young carers aged 8-17 years, of adults who are in-patients, or present at A&E, at the Royal Sussex County Hospital (RSCH) and are likely to have ongoing social care/health needs following discharge from hospital and those patients who have caring responsibilities of their own. Carers of people with dementia will be a particular priority group for this service. Carers of disabled children and carers of people who live outside Brighton and Hove are excluded”.

The interventions to be carried out by the project staff were anticipated\(^2\) to be as follows:

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\(^1\) Provided by Brighton & Hove during the setting up phase of the project.

\(^2\) As set out in the project description embedded within the Evaluation Expression of Interest statement.
• “carry out assessments of need for both carers and the person they are caring for and plan appropriate responses to ensure safe discharge and ongoing support to carers;
• help to bridge the gap between hospital and community support for carers;
• co-ordinate direct support at the earliest appropriate point, to individual carers of patients living in Brighton & Hove who come through A&E or who are admitted direct as either an emergency or planned care;
• work with carers to help avoid inappropriate admission and enable safe discharge by ensuring carers have the best possible level of health and social care support as early as possible;
• ensure carers have full information to understand what will be involved in caring for someone at home and linking carers with appropriate support and training (practical, physical, emotional);
• liaise with hospital and community staff, both NHS and social care to raise awareness of the needs of carers and the benefits of involving carers at all levels of treatment, care and discharge planning for the cared-for person.”

The evaluation was commissioned from the University of Sussex, and the evaluation team worked alongside the project for the full year of its operation.

2. Methodology

2.1 Overview

The overall aim of this evaluation was to identify the effectiveness of the pilot Carer Support Project in meeting its objectives and, in the light of those findings, to make recommendations for future service development.

Evaluation in this field is complex, given that outcomes are hard to measure, and a diverse range of factors in addition to service provision may influence their achievement for individuals. The evaluation nonetheless sought to identify changes brought about by the project and focused both on the processes of project delivery and on the outcomes achieved. The design made allowance for both quantitative data on project use and impacts, and qualitative data on the perceptions and experiences of those involved. The former provides evidence of changes taking place during carers’ engagement with the project; the latter assists in understanding the processes involved and helps to identify whether any changes identified in carers’ lives could be attributed to the input made by project activities. From the data, good practice in supporting carers can be identified.

The evaluation specification identified a number of priority areas of enquiry, and these underpinned the key objectives for the evaluation, which were to:

(f) report on the views of policy formulators, managers and front-line staff on the pilot carers’ support process;
(g) describe and analyse the processes and outcomes of support provided;
(h) assess the extent to which project activities meet their objectives of increasing carers’ capacity, confidence and participation, and reducing hospital bed-days, readmissions and care admissions;

(i) identify the views of carers on the support they experience through the project;

(j) identify the responses of hospital staff to carers as ‘expert care partners’;

(k) disseminate the evaluation findings through report and presentation formats.

It was anticipated that the researchers would draw where possible on data being routinely generated by the project’s operation, or using tools that could be integrated with the project’s work processes, and on data available through existing hospital statistics and records.

2.2 Methods

The evaluation was conducted in three phases. Although the project became operational early in 2010, the research team allowed for a lead-in period of 3 months before starting formal monitoring of cases, in order to allow time for practice to become established, with any early teething troubles ironed out, and to ensure that what was evaluated was the project’s operation in a period of relative maturity.

2.2.1 Phase 1: January – March 2010: Mapping expectations

(a) The project steering group was established, and included within its terms of reference the role of acting as an advisory group to the evaluation team. With the help of the group, the researchers were able to identify the range and quality of data available to the evaluation from the project’s routine records and processes, and to develop and pilot the additional evaluation tools necessary.

(b) Interviews were conducted with those responsible for the development, management and delivery of the pilot project and its activities. These respondents are referred to as key stakeholders in this report and included the project staff, their line managers, a senior management representative for the sector of the service in which the project was located, the commissioning manager and a representative of carers’ organisations – a total of 7 people. The purpose of the initial interviews was to make explicit the aspirations for the project and participants’ experience of its early stages of development. The interview schedule may be found at Appendix 1.

(c) A focus group of hospital staff associated with discharge processes was convened, with the purpose of exploring attitudes and beliefs in relation to carers as ‘expert care partners’ and identifying expectations of the carer support project held by those working in the hospital ward environment. This consisted of five nurses working for the discharge team, including the discharge team manager. The topic list may be found at Appendix 2.

(d) One of the researchers observed the project’s services in action through shadowing both care managers for a day in their workplace.

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3 For practical reasons, this focus group was in fact held early in Phase 2 of the evaluation.
2.2.2 Phase 2: April – September 2010: Gathering data on project use

The focus of this phase was on monitoring the project’s impact on carer wellbeing. Because the carers’ support project was open to all eligible carers, it was not feasible to establish a comparison group of carers who did not access the service. Indeed establishing the factors around which a comparison group should be constructed would in itself have been difficult, given that the outcomes for carers depend on factors well beyond the scope of the project’s remit, for example the health related outcomes of those for whom the carers care.

(a) As part of their routine process of assessment and case review with carers referred to their service, the project care managers administered carer wellbeing schedules which, suitably anonymised and with carers’ consent, could form part of the evaluation data. Following discussion in the steering group and consideration of a number of alternatives, the schedule selected was Part A of the Carer Wellbeing and Support Questionnaire (CWS) developed in 2009 by the Royal College of Psychiatrists and Rethink. The CWS comprises two sub-scales measuring well-being (Part A) and satisfaction with support (Part B), and is a reliable and valid measure of carer wellbeing and support4. Because Part B duplicated some questions which would be posed during the standard carer’s assessment the steering group advised that use of the CWS should be limited to Part A only in order to minimise demands on carers5. A copy of the schedule is available at Appendix 3.

Used as part of the initial assessment (Time 1), and again at case closure (Time 2) this schedule provided before and after measures of carer’ wellbeing. The project expected to conduct 20 carer assessments per month, giving a potential population of 120 cases during this phase of the evaluation. In the event, the number of carers whose Time 1 and Time 2 data were available to the evaluation team was considerably less, and resulted in 32 matched pairs.

(b) The original intention was also to use, at Time 1 and Time 2, data from the FACE carers’ assessment form completed routinely by the care managers (where permission was given by the carers for its anonymised release), and data from the record of case review at closure. In the event, as the project’s practice became established, it was clear that the carers’ assessments were not revisited at case closure, and therefore no comparable data at Time 2 was available. Whilst the 72 Time 1 FACE carers’ assessments passed to the research team provide interesting insight into the range of needs experienced by carers, a full analysis falls outside the focus of this evaluation and thus is not included in this report. However, a number of key facts describing the carers using the pilot service have been extracted and are described in section 4.2.2. From the demography of this larger group, it is also possible to identify that the smaller group of matched pairs did

4 Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., Pinfold, V. and Andiappan, M. (2009) Development and Validation of the Carer Well-Being and Support (CWS) Questionnaire: Report for the National Institute for Health Research Service Delivery and Organisation Programme. Its validity has been established in respect of carers in the context of mental health and dementia care; because it explores domains relevant to carers of other groups also, its use was considered appropriate in the context of hospital discharge, and following consultation with the developers there were no contraindications identified.

5 The CWS is in any event designed in such a way that its components can be administered separately.
not differ significantly from this larger sample on a number of key variables (age, sex, CWS scores at Time 1, and length of time the carer felt comfortable leaving the cared-for person alone).

c) For each of the carers in the total sample, the bed occupancy days of the cared-for person were identified (using anonymised data provided by the NHS Brighton & Hove Performance Analysis Team). The length of stay for each individual was compared with the length of stay for all patients in the same health resource group\(^6\), with a view to identifying any variation.

d) For each of the carers using the pilot project’s service, the number of hospital bed days used by the person they care for in the 6 months prior to referral to the Carer Support Project was compared to the number of hospital bed days in the 6 months following case closure by the project team, with a view to identifying any changed patterns. It is recognised that this is a very rough measure and that changed patterns of hospital admission will be attributable to a wide range of factors, not least the health status of the cared-for person.\(^7\)

e) All carers completing a Carers’ Wellbeing Schedule at Time 2 were also invited to participate in an individual semi-structured interview with a member of the research team. All who agreed to the release of their identity were contacted, and 20 individual interviews took place, exploring how carers had experienced the project’s service and the extent to which it had met their needs. The interview schedule is available at Appendix 4. The data from the interviews provides a more rounded picture of carers’ experience. Tests indicated the 20 carers interviewed were broadly comparable with those in the total sample who were not interviewed (n=52). Comparisons indicated no significant differences in sex, CWS scores at Time 1, and no significant differences in the length of time the carer felt comfortable leaving the cared-for person alone. However, carers in the interview sample were significantly older (mean 72.4 vs 62.0 years) than the non-interviewed group.

The approach taken in phase 2 aimed to identify changes that occurred for carers using the project. Although it is not possible to say with absolute certainty that changes are attributable to the project, the existence of patterns across a number of people can provide evidence of effect, particularly when amplified by the qualitative data.

2.2.3 Phase 3: October – December 2010: Mapping stakeholder satisfaction and analysing/reporting on the findings of the evaluation

(a) The interviews with the key stakeholders were repeated\(^8\), with a view to eliciting perceptions of the project’s achievements.

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\(^6\) After hospital admission, all patients are assigned a Health Reference Group number by clinical coders based on their primary and secondary diagnoses along with the procedures undertaken.

\(^7\) This aspect of the study is ongoing, due to the need for 6 months follow up time from the point at which recruitment to the evaluation sample ceased. It remains to be clarified what data will be available, in relation to which cared-for group. Any results will be reported in an update to this report during 2011.

\(^8\) It was possible to interview 6 of the 7 original respondents.
(b) The discharge team focus group was repeated with a view to identifying their experience of working with the project and any changes in perceptions of carers as ‘expert care partners’. Three discharge nurses participated in this second focus group, including the team manager and one nurse who had been appointed since the first group.

(c) It became apparent during the year that a number of carers were receiving support from the project but, because they did not undergo formal assessment, were not invited to participate in the full evaluation. The steering group felt it would be useful to know about the service they received, therefore a small sample (n=15) of those carers who received support from the pilot project but were not included in the evaluation were contacted by one of the care managers at the end of the project and invited to participate in a short telephone interview to give their impressions of the service. Nine agreed to participate, and consent sheets were returned by six. The data from these six carers were analysed.

(d) The quantitative data from questionnaires were analysed using a standard statistical package (SPSSv17) to identify frequencies and explore the nature and significance of changes in repeat measures scores; qualitative data from interviews were subject to thematic analysis using NVivo8 software.

(e) The present report was submitted to the advisory group and commissioner; presentation of the findings will be made to a suitable audience identified by the commissioner.

2.3 Research ethics and accountabilities

Ethical approval for the evaluation was granted by the University of Sussex Research Ethics Committee, with the result reported to and reviewed by the Research Governance Consultation Panel of Brighton & Hove City Council.

In going about their work, the evaluation team adhered to the standards and practices of ethical research, in particular:

- The evaluation was intended to preserve the well-being of those participating, and its outcomes were intended essentially to benefit carers and those they care for;
- Participants received clear information about the nature of the evaluation, and their informed consent was sought. Copies of relevant information sheets and consent forms may be found at Appendix 5;
- Participants knew that they could withdraw their consent at any time, including consent for the use of material or data they provided;
- The steering group sought to promote the full involvement of participants, including agreeing facilities for translation, interpreting and advocacy where necessary;
- In all contacts with carers, all effort was made to respond appropriately to sensitive content, and participants’ comfort was secured through adjustments to style and pace;
• Appropriate facilities were identified for participants to seek support with any personal issues arising from their participation;
• All data provided by participants have been anonymised in this report, and will be anonymised in any presentation or publication, unless express consent has been secured for participants to be named. Some steps have been taken, such as the amendment of minor details relating to individual carers, where it appeared there was a risk of identity becoming apparent. Key stakeholders have accepted that in the context of the evaluation of a small pilot service in a known location, their identity is known to others, but where possible care has been taken not to attribute views to any single individual;
• The confidentiality of data was limited only by the need to ensure the safety of third parties, whether adults or children, and participants were made aware of this at the onset of involvement;
• Data were treated in accordance with the requirements of the Data Protection Act 1998; other legal requirements (Human Rights Act 1998, Disability Discrimination Acts 1995 and 2005, Mental Capacity Act 2005), insofar as they relate to research, have been observed;
• All project staff working directly with carers in the course of this project had received satisfactory clearance through an enhanced check with the Criminal Records Bureau.

The evaluation team provided formal quarterly feedback to the commissioner, and informal communications took place where necessary.

3. Findings

3.1 Stakeholders’ expectations

Key stakeholders (n=7) were interviewed twice, once near the start of the evaluation period and once towards the end. The themes reported here are drawn from the first set of interviews, exploring expectations, aims and objectives in relation to the pilot project. The findings on experience and satisfaction from the second set of interviews are reported later in this chapter.

(a) Why was the project set up?

There was a degree of consensus about the issues that the pilot project was intended to address. These fell broadly into two related categories: concerns about the perceived low priority afforded to carers’ needs in the context of the hospital, and concerns about the ways in which carers’ capabilities were seen to impact on hospital bed occupancy. These were reflected in the dual emphasis contained within one respondent’s description of the Council’s responsibilities towards carers; these were seen as comprising:

• Statutory assessment of carers’ needs and the provision of services/resources to meet those needs;
• Engagement with carers in relation to their care of the service user.
These are interrelated but distinct areas of focus. In the hospital context, the goal was seen as being to ensure the best discharge route for the service user – with ‘best’ defined as the earliest possible discharge which addresses the user’s needs and takes the carer’s needs and capacities into account. But, it was pointed out, the arrangements made at the point of discharge should not be ones which tie people into long term decisions because they are made at a time when circumstances are changing rapidly. The more detailed work with carers often happens outside the hospital, in follow up by community teams.

Most key stakeholders reported that the project arose because it became apparent that carers’ needs were not being addressed effectively prior to discharge and that discharges as a result risked being delayed. Failure to meet carers’ longer term needs was also perceived as increasing the risk of the service user coming back into hospital.

“(We) recognize that if it is timely and appropriate, intervention with the carer can prevent re-admission because the carer’s needs (are) addressed.”

“Before the project it was difficult to operationalise these objectives because the focus was on the cared-for person; while we would take into account carers’ needs, the way we worked meant carers were not given time or space.”

Despite this recognition of carers’ roles, several stakeholders mentioned difficulties experienced in undertaking carers’ assessments.

“There were 2 carers’ assessments last year and these were seen as holding up work.”

“There were almost no carers’ assessments being done. If social work set up everything for carers it takes too long and we incur penalties because we are out of time.”

“In terms of carers’ needs being properly assessed, it wasn’t really happening in the hospital.”

“I welcomed this (project) and completely saw the point of it because people were being discharged too soon to carers whose needs have not been acknowledged or assessed.”

The reasons for these difficulties were well understood, but impacted too on other community-based services.

“The quality of service shouldn’t be determined by the level of demand, but at peak times (as when people might be queuing in the car park for admission) the pressure on discharge is exceptional.”

“It’s pressure of numbers, you know, needing to get people out quickly and so we get quite a lot of calls from carers where they haven’t been involved in discharge planning at all or they’ve had a call to say the person they care for is coming home...
The project was seen as providing the opportunity to step back and consider what was going on for carers during the period prior to hospital discharge, and to recognise that they were likely to be experiencing a whole range of transitions. The crisis of hospitalisation may have long term implications and a need for urgent readjustment in expectations and experience, whether that involves taking on a new, increasing an existing, or ending a previous caring role. The uncertainties involved in these transitions implied a need for a new way of managing the hospital/community interface in terms of how services are organised and delivered.

A further issue mentioned by some key stakeholders was the perceived need to change how carers are viewed by some professional staff, with examples given of carers being experienced by hospital staff as challenging, when in fact they are having difficulty coping, or merely want to be involved. Changing attitudes was seen as being a particularly difficult task.

“It’s a massive mountain to climb for carers... people’s attitudes and lack of insight, especially among the nursing staff. It needs a huge cultural change in how service is delivered. There is a huge and massive gap.”

The specific opportunity for funding to address some of these issues was reported as arising from an invitation from the Department of Health Regional Office and the Improvement and Efficiency Partnership, who were seeking to explore the benefits of health and social care collaboration to support carers in the context of acute hospital discharge. The development group was multiagency, involving both health and social care. Stakeholders particularly welcomed the opportunity to ring-fence some resource and protect it from competing priorities. There was also some reported involvement on behalf of carers in the development of the project. On a broad level, carers’ organisations had been involved in the Brighton & Hove Carers’ Strategy, under the umbrella of which this project was developed. More specifically, representatives of the local Carers’ Voice project were involved in interviewing for the project care manager posts, although more direct involvement in specific project planning prior to that point would have been welcomed. Carers’ perspectives were later contributed through the LINks network meeting, resulting in specific funding for Care Passports, a higher profile for local carers’ networks and resources within the project, and an emphasis on the importance of experienced outcomes as well as those that can be quantified.

(b) What is the project seeking to achieve?

Just as the problem was perceived to be multi-faceted, the component elements of any solution were similarly inter-related.

“It is crucial that whatever engagement with carers take place, it does not cause delay to discharge; but providing better services for carers can reduce delayed discharges.”

16
“It is pointless if it does not provide good outcomes for carers – but if it does not reduce bed days and prevent re-admission then it is not sustainable.”

Most key stakeholders mentioned all of the following sought outcomes for the project:

• To facilitate/prevent delay in hospital discharge;
• To reduce bed days;
• To prevent re-admission;
• To ensure good outcomes for carers.

Some stakeholders placed emphasis on the following activity objectives as means of achieving the sought outcomes:

• To assess carers’ needs;
• To link to the care pathway in the community;
• To set up programmes of support;
• To advocate on behalf of carers;
• To ensure early identification of carers.

“It was very useful that the project was really talking about dealing with carers from admission through to discharge because there’s always this emphasis on the discharge, because that’s often when the real problems start to show up, but in fact it needs to start right at the beginning.”

Allied to this, some key stakeholders explicitly mentioned the importance of raising carer awareness amongst hospital staff.

“Well I think it should be raising awareness amongst hospital staff in general because a lot of the problems ... are as a result of some of the ward staff maybe not making the proper referrals ... some wards have very good multi disciplinary team meetings and some don’t, so that’s where things can fall off the map.”

“I think helping social work and care manager staff to understand about carers assessments, and what can be the value of them and getting better safe planned discharges for carers and the people that they care for, so that their lives will be easier basically.”

There was more emphasis by some on the goal of setting up viable and enduring arrangements for the future, rather than merely ensuring timely discharge.

“I don’t think (there’s) a huge effect on shortening the hospital stay. In my mind (it’s) more about preventing re-admission and effecting a safe discharge rather than shortening a hospital stay.”

Central to this was the building of a supportive relationship with carers.
“Carers value support and knowing there’s someone they can ring who is on their side, (who is) there purely for them. It’s good ... because it’s acknowledging them ... (it) affects their experience of the hospital and of the discharge.”

Wide benefits throughout the system were anticipated by most stakeholders if the project could find ways of achieving these outcomes; mentioned in this respect were better emergency planning, more stable home care arrangements, more long term support for carers, more appropriate use of acute beds.

(c) How is the service different?

Key stakeholders were asked to comment on how the service was different from other services provided by the hospital social work team, and from other services for carers. Centre stage, in terms of perceived difference from other responses in the hospital context, was the project’s emphasis on the carer.

“Well I think the emphasis of the other workers is on the cared-for person to be honest. I mean... (in social work) you would obviously always be involving the family anyway, but that’s very different from really focusing on someone as a carer and they’re not always family either. Sometimes, you know, they’re neighbours friends, whatever. So I think that’s part of it and they often don’t necessarily see the carer on their own ... So yes I think the whole emphasis that they’re starting off with is just totally different.”

A further difference was perceived to be the preventive rather than reactive engagement with carers’ needs.

“This is a very different way of working. It has a proactive and preventive ethos. If we provide support at the beginning it will prevent later problems.”

Equally, the project’s educative role with other (particularly nursing) staff was emphasised as a distinctive element of the project’s work, with its focus on working to change perceptions of carers and of the value of working with them.

Another key difference was seen to be the mobility of the care managers – their ability to work beyond hospital boundaries, in effect following the carer back out into the community, after the patient’s discharge.

“The speed of work in the acute hospital setting means that it is different meeting the needs of carers in this context and social work could not go out of their way (in the past) to identify carers except within the requirement of their work (with the patient), and this stopped as soon as the cared-for person was discharged. Now (in the project) it is very different as the service continues post discharge. The person is followed out of hospital and continuity and ongoing support is very important.”
“They recruit referrals and follow them up in the community. This is instrumental in their success … the first couple of days post discharge are crucial to supporting the carer, it’s when reality strikes in their own environment.”

This mobility was seen as important in enabling the care managers to test out the viability of the support packages in the context of changing circumstances during what is often a transitional phase for the carer and the cared-for person.

The advantage of having a carer focus in A & E was also emphasised, bringing a new dimension to diagnosis and response in that environment:

“It is very different as well in A and E where the worker can pick up when someone is presenting there because the carer cannot cope. This is particularly important with people with dementia. This service is completely new in this context.”

Underpinning all of this was recognition that the underlying drivers for the service were very different from other hospital responses; the project drivers were seen as offering great scope for flexibility and creativity beyond the usual constraints.

“Its ‘drivers’ are different. The driver behind the regular hospital social work team is delayed discharge legislation; the driver behind IDT is demand. The carers’ care managers are rather “loitering with intent” – waiting to pick up their work downstream from those drivers. And they can in effect do anything they like provided they don’t delay the discharge.”

Thus the project care managers had the freedom of having a new service to develop.

In comparison with community based statutory services for carers, emphasis was placed on the different approach taken to carers’ assessments, which were reported as being conducted elsewhere primarily by telephone. The project offered the opportunity for a more relationship-based approach.

“You can’t build rapport over the phone”

Against this, one stakeholder mentioned the time pressure under which the project works, in the sense that the window of opportunity to make a difference is relatively short.

“It is much more time focused - the period of time to get results is much less than in the community.”

(d) What challenges will the project face?

Key stakeholders anticipated that the project would face a number of challenges in pursuing its objectives. Central amongst these was perceived to be the reliance of the project on the functioning of other systems within the hospital environment:
“The main challenge resides within the system – the fact that effectiveness is determined by the hospital’s approach to discharge planning, and that does not include a strong focus on planning for discharge from the point of admission. The care managers are dependent on health staff to make the referrals. During the carer’s experience of transition, timing may well be crucial, and a system working always at the last minute does not help.”

Associated with this was the challenge of ensuring that all staff knew about the project and understood what it could achieve; some stakeholders feared that this would take considerable time to establish, and that this too might make it difficult for the care managers to identify carers. The challenge would be compounded by the possibility that patients who are themselves carers may be overlooked, that young carers may not be recognised, and that the main carer may not be the person who visits the patient and will therefore be less visible to those upon whom the project would rely to identify those who could benefit from its services.

“The ward staff and social work team are not used to thinking in this way.”

“They may not see carers needs, you know, they might just be thinking about the cared-for person, ‘oh have they got the right equipment’ or ... you know, they may well not be thinking about issues such as the kind of emotional stress or the fact that a carer might be trying to hold a paid job as well as have their caring responsibilities.”

“There’s a huge gap in knowledge and understanding about carers and this goes back to training. Medics are trained to look at symptoms, not home life.”

The perceived lack of awareness about carers, combined with the strong drivers for efficient discharge of patients, were seen as combining to produce what almost amounted to a clash of organisational cultures:

“The Council pressure for a safe and timely discharge and the hospital pressure for discharge... There is a tension here.”

The question of how the project could carve out its position and exert the influence intended of it was seen as associated with the status of the workers in an intensely hierarchical hospital structure, with strongly embedded cultures, and how this would affect the power dynamics of their interactions with colleagues.

“They’re not at qualified social worker level even and they’re expected to maybe have an influence on people who are paid probably quite vast salaries compared to themselves and in a very, very hierarchical structure ... I think that would be unrealistic.”

Some stakeholders feared that the project care managers may risk being pulled into other urgent work at times of great pressure and demand. There was a perception that in the
early weeks it was taking a while for the project to settle into its own work, and to gain the support and space that had been intended.

Equally, and allied to the key difference identified above in relation to the mobility of the care managers to work outside the confines of the hospital, was the fear that they may have difficulty closing cases, and therefore hit capacity problems in relation to the turnover of their work.

“It will be a challenge for the care manager to be clear about boundaries and ending involvement. The care managers don’t have roles of other team members to emulate. We said 6 weeks follow up max – but they will use their judgement and make sure the carer is linked in to other services.”

“Its quite challenging to let go because there aren’t any rules ... there’s no one (for the project care manager) to pass it on to – its difficult.”

Associated with this was the recognition that 2 project care managers to cover the whole hospital would in itself be a challenge. Equally, there was concern about how far a small pilot project could make a difference in a short space of time, with no commitment to continuation, and the likelihood of carers’ provision needing to be mainstreamed rather than provided by specialists.

“I think you need a bit of specialism and a bit of integration and if you just have integration there’s a danger that people will get missed. I mean in the main access point they have integrated there but their carers assessments are only on the telephone and, you know, that obviously has its drawbacks but I suppose I just have concern with the hospital and that work being so pressurised that when the project finishes that carers might still fall off the map.”

There was a shared concern that because the project care managers were essentially lone workers, their own support systems may not be well established. A related issue was the question of where the project care managers’ case records were to be kept in the context of information flow systems already established. Equally, it was anticipated that managing workers with the degree of autonomy the care managers enjoyed would in itself be a challenge within established line management arrangements. Thus it was anticipated that regular systems may need to change and adapt to their needs in this respect, if their focus and way of working was to be maintained.

The nature of the hospital built environment, and the way in which space is used within the health setting, was also identified as potentially a challenge by several key stakeholders. It was recognised that there was no dedicated space for carers anywhere in the hospital environment and that this might make it difficult to carry out discussions with carers due to lack of privacy, both for content of interview and the expression of emotions.

One key area of uncertainty, and indeed concern, by some key stakeholders during the early stages of the project was the question of who would be the focus of the project’s intervention. It was thought by some that the project care managers would work only with
carers, whereas others thought that the care manager would carry the case of the cared-for person also. Arguments were raised in favour of both positions, but the strongest concerns raised were about conflicts of interest, and dilution of the focus on carers.

“If (the care managers) work with both (carer and cared-for person) there is the danger of the usual trap where working with the carer is the icing on the cake and their needs are not cared for properly. It’s easy for the carer to be sidelined, (with) a standalone worker this is much less likely to happen.”

“Well that concerns me a bit actually ... I mean I have heard it before, you know, you can go along to a cared-for person and maybe kind of tack on a carer’s assessment in effect. I’m not sure.”

(e) What will help the project to succeed?

A number of key personal attributes were mentioned as likely to support the care managers in being able to overcome these challenges.

“The personal skills of the care managers will be crucial – it takes special people to be able to operate effectively across that wide range.”

“The actual process itself, if you’ve got a good worker, (is) a really vital part of the experience, that (carers feel) recognised and that there’s somebody they could talk to.”

Confidence and assertiveness were seen as important, along with good networking and communication skills. Equally important was seen to be the question of manager support to help bring influence to bear on other managers who could then support their own staff in working with the project.

(f) How should the success of the project be measured?

Asked how the project’s success should be measured, key stakeholders referred to the following evidence that would be helpful:

- impact on delays to discharge and reduction of delayed transfers of care;
- impact on readmissions;
- whether carers have felt supported;
- how staff can work together on the wards to meet carers’ needs;
- whether outside the hospital environment carers are linked to support networks.

Some stakeholders considered that in order to be convincing in the context of future service planning, evidence would need to show impact for the cared-for person.

“Oh well that’s obvious. It’s going to be around reduced hospital admissions.”
“If the project stops re-admissions and the revolving door ... If this can be demonstrated it will be phenomenal.”

There was nonetheless some reference to tensions within the sought outcomes, and also recognition that the intervention of the project was small in scale in comparison with the totality of the systemic factors that would impact on its outcomes.

“There is some tension between hard and soft targets for the project, and a likelihood that the evaluation will not be able to tell us very much because the pilot is in effect a very small input into a very large and complex system. In judging results, it is important to recognise how the pressures within the system may compromise the project’s effectiveness, and to use that understanding in evaluating its performance. The project is not in control of everything that would make a difference ... it’s important to capture the complexities and interdependencies of the system.”

It was considered that expectations of impact should be modest, given the relatively small amount of staff time dedicated to the pilot, and that it was important for the pilot to evidence benefits at the individual level for those carers involved.

“The evaluation is essentially an opportunity to tell us what works well, or not so well, in this new way of working with carers. Impact on discharge is not solely determinative of its success.”

Impact for carers was valued both for itself and for its assumed positive impact for the cared-for person.

3.2 Overview of the project’s activity

The purpose of this section is to give a descriptive account of the project’s work, including statistics on its levels of activity, and examples of the types of interventions carried out. It is important to note that although the project comprised two care managers, their location and working environments were in fact quite different, the one from the other, and the differences between these contexts required some differences of approach as the service developed. One of the care managers was attached primarily to in-patient wards, the other worked primarily with the Integrated Discharge Team; this impacted significantly on the time available to make contact with and undertake work with carers - in the IDT context, for example, the target for discharge is 72 hours – and upon the type of work that was undertaken.

3.2.1 Number of carers in contact with the service

One hundred and eighty-two carers were seen by the pilot service between January and mid-December (96 by the care manager in IDT; 86 by the care manager on the wards). The numbers are broken down further in Table 1.
Table 1: Number of carers seen

<table>
<thead>
<tr>
<th></th>
<th>Carer’s assessment completed</th>
<th>Carer’s assessment not completed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDT Care manager</td>
<td>57</td>
<td>39</td>
<td>96</td>
</tr>
<tr>
<td>HST Care manager</td>
<td>65</td>
<td>21</td>
<td>86</td>
</tr>
<tr>
<td>Total</td>
<td>122</td>
<td>60</td>
<td>182</td>
</tr>
</tbody>
</table>

There were a number of reasons why carers who were referred or who had contact with the service did not receive a carer’s assessment. These included the carer declining the opportunity and wanting information only, the more transitory nature of contact in A&E so that whilst advice and information were provided they were not part of an assessment process, the cared-for person dying, or the care manager deciding it was inappropriate (for example when the person was not providing substantial care).

3.2.2 Carers included in the evaluation

(a) Demographic data on the carers

Seventy-two carers (45 woman and 26 men) agreed to participate in the study and had a carer’s assessments completed. The mean age of these carers at the beginning of the project, as shown in Figure 1, was 64.8, with 29 carers (40%) aged 70 or over, and 19 (26%) aged 80 or over.

![Figure 1: Number of carers by age at start of project](image)

Carers were White British by a large majority (n=66). Other ethnicities were as follows: White Other (n=3); White Irish (n=1); Chinese (n=1); Other Ethnic (n=1).

The employment status of carers is given in Figure 2 below. The majority of carers were either retired (51.4%) or not working (27.8%).
The relationships of carers to the cared-for person are given in Figure 3. The majority of carers were either partners/spouse (48.6%) or adult children (41.7%).

Nineteen carers (26.4%) had identified disabilities, impairments or health conditions that limited their ability to provide care, while 52 (72.2%) had none.

(b) **Health conditions of the cared-for person**

Table 2 gives a summary of the health conditions and impairments of the cared-for person mentioned in the carer’s assessment. These numbers are under-estimates, however, since the carer’s assessment does not have a specific question on this. Rather, the information has been gleaned from other parts of the assessment.

It is clear from the table that carers are dealing with a wide range of conditions, with at least 22 carers (30.5%) naming three or more of these categories. Mobility issues were the biggest single category, with 49 carers (69%) mentioning these. The next largest categories were dementia/memory loss (19 carers – 26.4%) and heart conditions (17 carers – 23.6%).
The ‘other’ category in Table 2 contains a large number of different conditions mentioned by only one or two carers.

**Table 2:**
Health conditions/impairments of cared-for person mentioned in carer’s assessment

<table>
<thead>
<tr>
<th>Health condition/impairment</th>
<th>Number of carers mentioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility issues; legs; spine</td>
<td>49</td>
</tr>
<tr>
<td>Dementia; memory problems; confusion</td>
<td>19</td>
</tr>
<tr>
<td>Heart; hypertension; angina</td>
<td>17</td>
</tr>
<tr>
<td>Other mental health</td>
<td>8</td>
</tr>
<tr>
<td>Incontinence/stoma/catheter</td>
<td>8</td>
</tr>
<tr>
<td>COPD; Pulmonary Fibrosis; emphysema</td>
<td>6</td>
</tr>
<tr>
<td>Visual impairment; hearing loss</td>
<td>6</td>
</tr>
<tr>
<td>Cancer</td>
<td>5</td>
</tr>
<tr>
<td>Arthritis; osteoarthritis</td>
<td>5</td>
</tr>
<tr>
<td>Renal</td>
<td>5</td>
</tr>
<tr>
<td>Stroke</td>
<td>4</td>
</tr>
<tr>
<td>Parkinsons</td>
<td>4</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>3</td>
</tr>
<tr>
<td>Asthma</td>
<td>3</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3</td>
</tr>
<tr>
<td>Other (alcohol; specific diseases; neurological; diverticulitis; general pain)</td>
<td>32</td>
</tr>
<tr>
<td>No information provided</td>
<td>6</td>
</tr>
<tr>
<td>Three or more of the above</td>
<td>22</td>
</tr>
</tbody>
</table>

(c) Care provided by carers
The carer’s assessment contains questions about the level of care/support provided in a range of different areas. These are summarised in Table 3.

This table illustrates that carers are providing support over a wide range of areas. Over half of carers provide all or most of the support needed in medication and health-care, emotional support, managing finances, transport/escorting to appointments, ensuring safety or well-being, company during the day, shopping, support during the night, mealtimes, housework and communication. Between 40% and 50% of carers provide all or most of the support needed in getting up in the morning, mobility (e.g. moving into bath, onto chair or toilet) and getting ready for bed.

In terms of how long carers felt able to leave the cared-for person on their own, 16 (22.2%) said they could not leave the person alone, a further seven said 15 minutes or less, and a further nine said an hour or less. Overall, 45.1% of carers would only leave the cared-for person alone for between zero and 60 minutes. Only 18.3% of carers would leave the person for over three hours.
### Table 3: Type of support provided by carers (frequencies and percentages)

<table>
<thead>
<tr>
<th>Type of help provided by carer</th>
<th>The person does not need support</th>
<th>I provide all or most of the help needed</th>
<th>I provide about half or less of the help needed</th>
<th>I do not provide any help in this area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>2 (2.8%)</td>
<td>39 (54.2%)</td>
<td>28 (38.9%)</td>
<td>2 (2.8%)</td>
</tr>
<tr>
<td>Getting up in morning</td>
<td>3 (4.2%)</td>
<td>30 (41.7%)</td>
<td>25 (34.7%)</td>
<td>13 (18.1%)</td>
</tr>
<tr>
<td>Housework</td>
<td>0</td>
<td>57 (79.2%)</td>
<td>14 (19.4%)</td>
<td>0</td>
</tr>
<tr>
<td>Mealtimes</td>
<td>18 (25%)</td>
<td>37 (51.4%)</td>
<td>10 (13.9%)</td>
<td>6 (8.3%)</td>
</tr>
<tr>
<td>Mobility</td>
<td>10 (13.9%)</td>
<td>33 (45.9%)</td>
<td>16 (22.2%)</td>
<td>12 (16.7%)</td>
</tr>
<tr>
<td>Getting ready for bed</td>
<td>8 (11.1%)</td>
<td>29 (40.3%)</td>
<td>18 (25%)</td>
<td>16 (22.2%)</td>
</tr>
<tr>
<td>During night</td>
<td>15 (20.8%)</td>
<td>37 (51.4%)</td>
<td>9 (12.5%)</td>
<td>10 (13.9%)</td>
</tr>
<tr>
<td>Shopping</td>
<td>1 (1.4%)</td>
<td>61 (84.7%)</td>
<td>7 (9.2%)</td>
<td>2 (2.8%)</td>
</tr>
<tr>
<td>Company during day</td>
<td>0</td>
<td>58 (80.6%)</td>
<td>10 (13.9%)</td>
<td>3 (4.2%)</td>
</tr>
<tr>
<td>Making sure person is safe and well</td>
<td>0</td>
<td>62 (86.1%)</td>
<td>9 (12.5%)</td>
<td>0</td>
</tr>
<tr>
<td>Transport or escort</td>
<td>1 (1.4%)</td>
<td>44 (61.1%)</td>
<td>7 (9.7%)</td>
<td>19 (26.4%)</td>
</tr>
<tr>
<td>Managing finances</td>
<td>3 (4.2%)</td>
<td>54 (75%)</td>
<td>13 (18%)</td>
<td>1 (1.4%)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>2 (2.8%)</td>
<td>62 (86.1%)</td>
<td>7 (9.7%)</td>
<td>0</td>
</tr>
<tr>
<td>Medication or health care</td>
<td>3 (4.2%)</td>
<td>47 (65.3%)</td>
<td>16 (22.2%)</td>
<td>5 (6.9%)</td>
</tr>
</tbody>
</table>

Sixty-five (90.3%) carers provide more than 35 hours care per week, and 59 (81.9%) indicated that they would like more support in their caring role. Fifty-nine carers (81.9%) also indicated there were reasons they might not be able to provide care in the future.

At the time of the assessment, 51 (70.8%) said they had arrangements in place for cover, with 32 (44.4%) having arrangements in place for emergency back-up cover. Correspondingly, 20 (27.8%) had no arrangements for cover, with 39 (54.2%) having no emergency back-up plan.\(^9\)

#### 3.2.3 Examples of the interventions undertaken by the project

The purpose of this section of the report is to capture some of the ways in which the project staff worked, interpreting their terms of reference and objectives in ways that best suited the organisational context in which they were located. The descriptive data have been drawn from interviews with the care managers and other key stakeholders, from documents about the project, and from case vignettes illustrating the type of work undertaken. Where actual cases have been used as illustration, details have been changed to ensure anonymity is maintained in relation to the identities of individual patients and carers.

\(^9\) When totals do not add up this is due to missing data.
Sometimes carers need someone who can pick up on their own anxieties and needs when the acute focus is on the cared-for person, and where necessary put in place practical interventions that can make all the difference. Communication with others on the carer’s behalf is also important.

An 88 year old man was caring for his wife with dementia, who was admitted to hospital following a fall resulting in a fractured femur. The fall was attributed to a medical condition that would require a prolonged stay in hospital, and the carer was anxious about his wife wandering on the ward, and being able to communicate her needs and preferences to busy ward staff. A care passport was completed identifying her likes/dislikes and this reassured the carer that they would be taken into account. Spending time with the husband made it apparent to the project care manager how very anxious he was and when his wife was discharged a home visit was carried out. He was able to open up about how confined he was feeling, and how concerned he was about his wife’s increasing aggression towards him. This information was shared with the Independent Community Assessment Team, who arranged for his wife to attend a day centre 2 days a week. At follow up by the project care manager, the husband sounded happier and more relaxed and was very happy with the new arrangement.

Carers of people with dementia are sometimes grieving already because they are living with a different person; they may be isolated, may feel guilty and ashamed, and may be hiding the true picture. The project gives carers the opportunity to open up.

A 90 year old woman had been providing care for her husband, with Alzheimer’s Disease. She was admitted to hospital for her own medical needs, but displayed intense anxiety and agitation about her husband, who was being looked after by other family members in her absence. The project care manager learned from the family that their mother had been struggling with caring for her husband, who was very demanding and also verbally and emotionally abusive towards her. He could not be left alone due to risk of falls, and she was very isolated, and also sleep deprived as he woke 3-4 times during the night. The project care manager was able to give her a chance to share the underlying distress: in her words: ‘It is hard when the man whose sweetheart you’ve been for 65 years does not know you. I feel terrible that I cannot care for the man I love, but I feel washed out and can’t handle anything’.

The project care managers were sometimes able to build the first steps of trust that would enable other services to follow through with specialist support.

A young woman of 22 was caring for her grandfather, who was dependent on her for most daily living activities, including emptying the commode, cooking, household tasks, arranging medications, company, and emotional support. She had recently attended college as part of developing work skills and was looking for part time work so she could continue caring, because ‘family are priority and that’s the way it has to be’. Her grandfather was reluctant to engage with formal care due to the cost. The project care manager built a supportive relationship: “I was not skilled enough to counsel her, but I could give her time, no-one else could do that.” She agreed to be referred to the Young Carers’ Project, through them attending outings and courses; with their support she gained employment in catering. Her grandfather died recently and she asked the Young Carers’ Project to let the project care manager know; the Young Carers’ Project confirmed at the same time that they would continue to support her.

Carers may neglect their own needs because of the more pressing demands of the cared-for person, and this can sometimes result in a crisis which is picked up by the project team.
A 69 year old man, a carer, was sent to hospital for an emergency blood transfusion leaving at home alone his wife who was diagnosed with arthritis, had a history of falls, and was confined to the bedroom. Initial arrangements were being made for support to his wife in the home, but the hospital then arranged for his treatment to be given as an outpatient. The project care manager undertook a home visit and carried out an assessment, following which the couple were referred for financial assessment due to their concerns about the costs of services, and the Emergency Back Up registration details were updated. The project manager advocated on their behalf with the district nurse, the GP, Access Point and a charitable organisation involved in order to instigate timely interventions relating to the wife’s health needs (for example catheterisation to prevent the need for the carer waking during the night), and for services to be set up that would prevent admissions to hospital.

The project care manager was sometimes able to provide intensive support in circumstances where no other source of such support would have been possible, picking up on the emotional impact of the health deterioration of the cared-for person.

A woman in her 70s with Parkinson’s Disease was admitted to hospital from respite placement following a fall. Her son, who lived with her, was her main carer, and the case was referred to the project care manager due to the possibility of an increase in the level of care needs. The care manager provided telephone updates to the son, as his mother became increasingly ill, and encouraged him to discuss matters with the ward; he identified on a number of occasions that he did not know what was going on and ‘wanted answers’. The care manager arranged meetings with the family and the medical and nursing staff so that communication could be established; these took place on 3 occasions, with the project care manager attending to support the carer. The care manager subsequently supported the carer and family when their mother was placed on end of life care. Later, they provided bereavement information and condolences on

Another advantage of the service is that the care manager can act as a single access point for carers and is able to provide a personalised service once the cared-for person has been discharged and has had time to adjust to their new situation.

A 98-year old man was receiving an existing package of care (2 visits per day), and declined to have it reviewed on leaving hospital. The carer, his daughter, was concerned that this would not be enough and contacted the Social Work Team. The care manager carried out a home visit five days after discharge, allowing the cared-for person time to experience being at home again. He agreed to have a third daily visit, which the care manager arranged. The care manager also discovered the cared-for person was not wearing his Carelink alarm, and arranged a wrist alarm that was more acceptable to him, also activating his account with Carelink. The result of the care manager’s involvement was that the father’s increased care needs were met as well as the concerns of the daughter. Traditionally, this patient would have gone home without a formal review as they had declined this process. However as the care manager was able to stay in touch with the family after discharge, s/he was able to respond to concerns and needs that became apparent later without the delay of referring to another part of Social Services.

In some cases, care managers became involved with complicated family dynamics when more than one person might be identified as a carer.

One man, caring for his parents, was struggling to cope with his parents’ increased needs following his mother’s discharge from hospital, after which his father also began to need additional support. The care manager set up a package of care for the mother, and completed a carer’s assessment with four family members. The care manager also arranged funding for transport costs for one of the daughters, Carelink and the emergency back-up scheme. There were frictions within the family about call times from the Reablement Team, leading to the service almost being cancelled. The care manager took up the role of liaising with this service and helped avoid the support being lost. Ultimately, the care manager conducted multiple referrals, over fifty phone-calls, and many home visits.
### 3.3 Impact on length of hospital stay of the cared-for person

The senior performance analyst of the PCT extracted the actual length of stay (LoS) for all patients whose carers were recorded as having used the project’s service between 2/1/10 and 9/9/10, as well as their dominant Health Reference Group number (HRG)\(^{10}\).

These were compared with the average LoS for all patients in each HRG on the national recording system (excluding those patients whose carers had used the project’s services). This allowed comparison between the actual LoS for each patient in the carer cohort with what would be expected based on averages in the population.

Sixty-one patients in the carer cohort were found on the Secondary User Services database. Due to missing HRG information on one patient, sixty were included in the final analysis. Others not included in this analysis were patients whose NHS ID, Local Patient ID or admission dates did not match the records (n=50). It should be noted that in a small number of cases, it was the carer who was in hospital rather than the cared-for person. This was the situation for two of the carers who participated in the carer interviews; data on the number in the larger sample was not available.

Because the largest number of patients in the carer cohort who shared an HRG was three (with most participants being in their own unique HRG), it was not possible to group the patients to perform meaningful statistical tests on any one HRG. Similarly, because individuals are being compared with group averages, parametric tests could not be performed.

#### Table 4: Average LoS in Carer Cohort Compared to Average LoS for matched HRGs

<table>
<thead>
<tr>
<th></th>
<th>Actual LoS (days)</th>
<th>HRG average LoS</th>
<th>HRG average LoS excluding cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>9.49</td>
<td>5.05</td>
<td>4.75</td>
</tr>
<tr>
<td>Range</td>
<td>87</td>
<td>16.86 (ave)</td>
<td>16.06 (ave)</td>
</tr>
</tbody>
</table>

Although Table 4 indicates that average length of stay for the cohort is higher than the average of the HRG averages, this is not a meaningful comparison. The carer cohort numbers are affected by a number of extreme cases (giving a range of 0-87 days). Extreme cases in the HRG samples have been compensated for the fact they have already been averaged over large numbers of cases (resulting in a much smaller range of 16 days).

A more meaningful analysis compares the groups in ways that are not affected by these extreme individual cases. Two non-parametric tests were performed. These simply compared the number of patients with shorter-than-average stays to those with longer-than-average stays. If there was no difference between the carer cohort and what might be expected from their HRG, these numbers would be expected to be roughly equal.

\(^{10}\) After hospital admission, all patients are assigned a Health Reference Group number by clinical coders based on their primary and secondary diagnoses along with the procedures undertaken.
Figure 4: Number of patients with shorter vs longer than expected stays in hospital.

As Figure 4 demonstrates, the number of those with shorter-than-expected stays was 38, compared with 22 patients with longer-than-expected stays. A chi-square test suggests this difference is significant (chi-square = 4.267, df = 1, p = 0.039). It can be concluded from this that significantly more patients in the carer cohort had shorter than expected LoS than had longer than expected LoS.

One caveat needs to be taken into consideration when understanding these results. The carer cohort sample contains only patients with carers, whereas the HRG total sample includes patients with and without carers. The samples are therefore only partially comparable.

If it is assumed that patients without identified carers tend to stay in hospital longer because they cannot be supported at home as easily, then it might be expected that the HRG averages would be higher anyway. If, however, it is assumed that patients without carers are moved more quickly to other care facilities, or that patients with carers tend to be older and have greater pre-existing disabilities, then it might be expected the HRG averages would be lower than the carer cohort sample. Either way, the interpretation of this result is difficult.

3.4 Impact on carer wellbeing: Time 1/Time 2 comparisons

3.4.1 Sample characteristics

Thirty-two carers filled in the Carer’s Wellbeing Scale (CWS) at both Time 1 and Time 2. Comparing this sample with the group who only did the CWS at Time 1 (n = 40) shows they did not differ significantly in age, sex, length of time they felt comfortable leaving the cared-for person, or any of the scores on the CWS at Time 1.

The mean age of this group was 67.4, with 19 women and 13 men. The mean longest period the carer felt comfortable leaving the cared-for person alone was 184 minutes. Employment status of this group tended towards more people in retirement (59.4%) compared to not working (15.6%) and in full-time work (12.5%). In terms of relationship to the cared-for person, 53.1% were partners/spouse and 34.4% were adult children.
3.4.2 Time 1 – Time 2 Comparisons

The average time elapsed between participants completing the CWS at Times 1 and 2 was 74.6 days (SD = 47.6). The range was 19 to 191 days.

The Carer Wellbeing Scale consists of 32 questions covering a range of issues:

- Concerns about role as carer (5 questions)
- Relationship with cared-for person (6 questions)
- Relationships with family/friends (4 questions)
- Financial situation (3 questions)
- Own health (2 questions)
- Emotional well-being (6 questions)
- Stigma (1 question)
- Own safety (2 questions)
- Safety of cared-for person (3 questions)

Scores were compared at Time 1 with those at Time 2 on all these areas separately, as well as on the total for all 32 questions combined. In all cases, lower scores reflect a more unfavourable state, therefore increases over time indicate improvement.

It should also be noted that the number of questions varies according to which issue is being measured. This affects the total score possible on each dimension, since each question is measured on a scale of 0-4 (‘a lot’ to ‘not at all’). For example, the total scale consists of 32 questions, with a possible total score of 128. The Role as Carer sub-scale has 5 questions (total possible score of 20), whereas the Own Health sub-scale has only 2 questions (total possible score of 8).

As can be seen from Figures 5 and 6, seven of the nine well-being domains showed an improvement over time, although in most cases these improvements did not reach significance.

Figure 5: Carer wellbeing scores at Time 1 and Time 2
Using Wilcoxon tests, there was one significant difference on the subscale ‘Concerns about your role as a carer’ (see Table 5 below), where a more positive evaluation was given at time 2 compared to time 1 (9.3 vs 7.9; \( p = 0.034 \); Wilcoxon Test).

**Table 5: Role as Carer Questions**

<table>
<thead>
<tr>
<th>Concerns about role as carer</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>During the past 4 weeks, how concerned were you about</em></td>
</tr>
<tr>
<td>• Not having enough time to yourself?</td>
</tr>
<tr>
<td>• Having to put the needs of the person you care for ahead of our own needs?</td>
</tr>
<tr>
<td>• Not being about to take a break from caring?</td>
</tr>
<tr>
<td>• Not being able to plan for the future?</td>
</tr>
<tr>
<td>• Not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?</td>
</tr>
</tbody>
</table>

In addition, the total scale score (76.5 vs 71.9) and the sub-scale on ‘Own Health’ (4.4 vs 3.6) showed improvements that approached significance (\( p=0.077 \) and 0.076 respectively). However, whilst encouraging, these results should be interpreted with caution because they did not reach the threshold at which the difference could be considered reliable.

In terms of comparison between the results for carers in the two separate teams (HST and IDT), the overall sample of 32 was split between the teams as follows, with IDT carers significantly more likely to complete a Time 2 questionnaire.

**Table 6: Comparison between HST and IDT sub-groups of carers**

<table>
<thead>
<tr>
<th>Team</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>HST</td>
<td>47</td>
<td>13</td>
</tr>
<tr>
<td>IDT</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>72</td>
<td>32</td>
</tr>
</tbody>
</table>

The two groups differed to some extent, in that the HST users had significantly better emotional well being at Time 1, and the IDT users were significantly less concerned about stigma (being treated differently because of the condition of the cared for person) at Time 2. There were no differences in age, or in any of the other CWS scales.
In terms of comparison between Time 1 and Time 2, at Time 2, the HST users showed significant improvement in their degree of concern about their role as a carer – i.e. a reduction of that concern – and improvement approaching significance in terms of their overall well-being score. IDT users showed significant improvement (i.e. reduction) in levels of concern about their own health.

It is not, however, easy to interpret differences between the two sub-groups because the samples are small (13 and 19), and are not necessarily directly comparable, given the different circumstances in which the service was being delivered and the different response rates at Time 2.

### 3.5 Impact on carer experience: carers’ perceptions

The main findings reported here come from the interviews with carers who completed both Time 1 and Time 2 Carer Wellbeing Scales and subsequently agreed to be interviewed by the researchers.¹¹

#### 3.5.1 The interview sample

Twenty carers were interviewed. Comparing this sample with the group who did not participate in interviews (n=52) shows that the group interviewed were significantly older (mean of 72.4 years vs 62.0 years; Mann-Whitney U = 253.5, p = 0.026). There were 10 women and 10 men in the interview group. Twelve carers had contact with the IDT care manager for carers, and eight had contact with the ward-based care manager for carers.

Nineteen (95%) provided over 35 hours care per week, 15 were retired (75%), 19 (95%) were White British (1 was White Irish). Thirteen (65%) were partners/spouse of the cared-for person, and 6 (30%) were adult children. The mean longest period the carer felt comfortable leaving the cared-for person alone for was 161 minutes.

In order to check that this sample is representative of the larger group, Mann-Whitney tests were carried out to compare the interview sample with those who were not interviewed on the Carer Well-Being scores at Time 1. There were no significant differences in total well-being scores, nor were they any differences in any of the sub-scales scores. Similarly there was no significant difference between those who were and were not interviewed in the mean longest period the carer felt comfortable leaving the cared-for person alone.

Table 7 gives an overview of the carers’ situations at the time of initial assessment, and before the intervention of the pilot project.

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¹¹ There were a number of carers who received input from the service, but who did not participate in the evaluation. In order to gain some understanding of the support offered to this otherwise ‘invisible’ group, short telephone interviews were carried out by one care manager. Their experiences are described at the end of this section (3.5.3).
Table 7: Summary of questions relating to caring at time of initial assessment

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the carer have disability or health conditions?</td>
<td>6 (30%)</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>Were arrangements for cover in place?</td>
<td>12 (60%)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Was there an emergency back-up plan in place?</td>
<td>8 (40%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Would the carer like more support?</td>
<td>14 (70%)</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>Any reason the carer cannot continue in the future?</td>
<td>17 (85%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Does the person provide care for over 35 hours per week?</td>
<td>19 (95%)</td>
<td>1 (5%)</td>
</tr>
</tbody>
</table>

3.5.2 The reliability of the interviews

To assess the reliability of the interview data, a partial check was undertaken on its quality by comparing the details provided by the carer on the specific supports received with some brief notes compiled by one of the care managers. This section describes the type of inconsistencies that we found.

Of the 20 carer interviews, seven were matched with summary details recorded in the care manager’s log in order to provide some indication of the consistency between carer accounts of the service they received and that of the service workers. It should be noted that the care manager log does not mention everything the care manager did – only a selection of information that the care manager judged particularly pertinent has been recorded in each case. It is not equivalent to an exhaustive interview with the care manager on what s/he did in each case.

However, the carer interviews were an opportunity for the carer to report everything they could remember, so if there is something the care manager reported that the carer did not, this can be identified as an inconsistency. This can then be used to highlight some of the issues of reliability that affect carer interviews.

It is not the purpose here to comment on who is correct in any specific case (carer or care manager), but simply to note where the two informants provide different versions of the contact and support provided. However, since the carer was more likely to be in a difficult and stressful situation at the time, often meeting many different teams and workers, and as the care manager took notes for the log, it can be assumed that in some cases these inconsistencies represent omissions by the carers. Indeed, the carers often claimed that they found it difficult to remember what had happened.

Many of the issues that were mentioned in the care manager log were mentioned also by the relevant carers. However, there were issues for each of the seven cases which were not mentioned by the carer. If the carer was responsible for the inaccuracy (rather than the care manager), the inconsistency might have been due to failures of memory, lack of awareness
that the care manager had provided the support (e.g. inter-agency communications from the office; when several professionals were involved and the carer did not know which had been responsible), or because the carer did not consider the support to have been of a type worth mentioning (e.g. phoning to remind them to do things; offering emotional support).

The following are a few examples of support the care manager reported in his/her log but which the carer did not refer to in their interview:

- Being referred to Age Concern and Meals on Wheels; being referred to the Carers’ Centre.
- The care manager persuaded a mother and daughter not to cancel a care package which they subsequently admitted they did need. The care manager also facilitated early discharge on the request of the patient by making sure the daughter was able to care for several days until a care agency could re-start their visits.
- When dealing with the highly-distressed husband of a woman entering a care home, the care manager liaised with the care manager of the care home to provide full background information.
- The care manager was alerted by another professional that a carer s/he had previous contact with was becoming highly stressed. The care manager got back in contact to offer more support and helped arrange respite care.
- The care manager did a home visit in order to fill in a form with the carer who did not want it sent through the post. The care manager also sought advice over appealing against a funding decision and wrote the carer a letter about the appeals process.

This suggests that the support described by the carers in the analysis of the interviews is likely to omit some of the support they did receive from the pilot project. It should also be noted that because of the number of professionals involved just after discharge, carers were sometimes unsure who had been responsible for what, and may have mentioned some services they received which had actually been arranged by other teams (e.g. occupational therapy).

3.5.3 Analysis of interviews

The analysis is divided into five themes:

- Experiences of caring: identity, attitudes and impact
- Experiences of the pilot service
- Outstanding needs and non-uptake of services
- Experiences of hospital
- Other complaints and suggestions
(a) Experiences of caring: identity, attitudes and impact

(i) Carers’ views of their role

Seven carers seemed to accept their role as carers either as a natural part of their role in the family, because they enjoyed it, or because they were good at it. For example, one woman said: “I love doing it. It keeps me busy. I’m quite happy with it; it occupies my mind.”

Another said: “It’s the way my generation is. You look after your family … We chug along quite happily.” This participant didn’t consider what she did as ‘caring’ because “‘You look after your own; you look after your children, you look after your husband.” She was one of two participants who said they did not see themselves as carers. The other, a man, said that “I don’t do much for her.”

Others presented a stoical face which seemed infused with a sense of inevitability, adaptation, and duty. For example, one carer said: “It’s my responsibility and I’ve got used to doing it my way,” while another said “At first it’s a bit daunting, but then you get used to it and carry on. Then there’s another hurdle and you get used to it. You just adapt.”

Sometimes there was also a sense of mastering the frustration in the role:

“You’ve got to do things yourself. Many times I could scream my head off and I wish I could get some help. But I don’t know what help I want. So I calm down and carry on.”

Five others expressed a sense of frustration in the way that the role had taken over their lives, had been forced on them, or had affected their relationship with the person they cared for. For example, one woman caring for her mother said:

“… the system says there’s someone doing that, but someone is doing that as a family member or caring person. They don’t want to be doing everything else, putting cream on their bottom and the whole works. I’ve had to do all sorts of things that I never thought I’d have to do for my mum. If affects your relationship on some level. And you are getting older yourself … this should be a time I’m thinking about me more.”

A man acting as carer to his friend said “I shouldn’t be doing it, but I’m caught in the trap now.” A similar feeling was expressed by a man who described his partner’s illness:

“I said I didn’t want to be classed as a carer because I didn’t want the responsibility. But I became a carer. You just do. I really wanted a carer to look after him, but I didn’t ask (care manager), I just said I didn’t want to be a carer.”

(ii) The impact of caring on carers

A variety of negative effects on carers’ health and wellbeing were described. The most common was tiredness and fatigue, which eight carers talked about. This was from a combination of getting older, of not sleeping well because of the needs of the cared-for person during the night, and of having to attend to many issues in the course of a day:
“At times I’m absolutely shattered. At midday I’m shattered — I wish it was bed-time. I feel mentally exhausted. I could scream.”

Five people linked this with becoming frustrated and aggressive or aggravated. This was either due to difficulties dealing with services, or with their role as a carer.

“He’s up 7 or 8 times a night. The main thing is the tiredness. He’s got no coordination. You get irritable, but that’s part of being tired. You get tearful but it’s all part of tiredness.”

“Very often it falls to one person so that one person gets isolated and ill, and also gets blocked by the system sometimes because they’re not knowing to ask because they’re so tired you end up being quite aggressive or just desperate.”

This person said later:

“...I have spoken to one of the senior managers about that (complaint about care coordination) but then they try and make you the problem. And it’s a self-fulfilling problem that, because when you’re so frustrated you perhaps become the problem.”

Six people mentioned feeling worried or stressed, or described temporary health conditions associated with stress (e.g. losing weight, ‘flaking out’). One of these, and a further three carers, described themselves as either very depressed, depressed, a bit depressed or tearful/irritable.

Caring also affected people’s relationships. Four people mentioned that it left them little time for friends (3) or that it interfered with intimate relations (1). In three cases this was because of the time commitment, but for one woman it was because the cared-for person (her husband) tried to stop her going out. Two carers (both adult children caring for their mothers) described their lives as being completely consumed by their caring role:

“I suppose my life stopped about 8 years ago. I feel I’ve married my mother. I’m the stand-in husband. If my father were alive I’d be doing other things.”

“Your life just gets lost.”

Juggling their own health problems was mentioned by five carers. The stress of caring was described as either causing health problems or as exacerbating existing conditions, and in turn this affected the participants’ ability to care.

“He was trapped in the bathroom. I couldn’t open the door and started to panic. They took him off to hospital and I had a heart attack a week later. I think it’s all connected; I think it’s the stress of it. As you get older... he’s very heavy to move .... I’m not so able to cope since the heart attack, but I do cope.”

A number of other effects were mentioned by carers, such as it making them lose their sense of fun and not being able to go out without looking at their watch.
Two carers stated that being a carer had little effect on them:

“Not much really. I’ve got a little less social life but I’ve got no money anyway. Most of my money goes on the mortgage.”

(iii) Carers’ confidence in their ability to continue caring
Ten people felt reasonably confident in their ability to continue caring. For these carers it was often described as being a natural thing to do, and they felt reasonably competent in meeting the demands of the role.

“I’ve always done it. I don’t think about it. We’ve been married 69 years. Yes, I can continue at the moment. Yes. It’s natural to do it.”

“Fine. I love doing it. It keeps me busy. I’m quite happy with it. It occupies my mind.”

Eight people expressed concern about their ability to continue caring, either now or in the future. These concerns often focussed on their ability to cope as they became older or less healthy, or as the cared-for person’s health or mental abilities deteriorated. Often these concerns were linked with expressions of a high level of stress or fatigue (described above).

“I try to do the best but there’s nothing I can do, really. It does worry me a bit when she gets these bad turns ... I want to do more but there’s nothing I can do ... I want to carry on, yes, but I do feel absolutely worn out from time to time.”

“He’s more demanding; he needs me more. He won’t have a carer and won’t go into respite. So it’s 24/7. Either he’ll snap or I will.”

(b) Experiences of the Pilot Service

A key focus of the interviews was on carers’ experiences of the pilot service. However, seven carers found it difficult to remember exactly what the pilot project did for them. This was because the intervention occurred behind the scenes, because it happened some time ago and the person could not recall what was discussed, because there were a number of professionals involved and they were not sure who had been responsible for arranging what, or because they had met the care manager in a time of great stress and worry. One carer could not remember at all, while others remembered some help but were not sure about other supports they received. Thirteen carers, however, did not express any uncertainty in their recall.

It is important to note, however, that the reliability check described above does indicate that the carers are likely to have failed to report some of the support offered by the service. Another important caveat to these findings is that while carers sometimes did not report support they did receive, they are also likely to have named supports that the pilot service did not arrange. This is particularly the case when multiple workers and teams were involved, and the carer was unclear who had arranged what.
(i) Type of support provided by the pilot service
Overall, 18 of the 20 carers interviewed valued the service and described some of the ways it had helped them. Two people said the service had not been helpful and had done nothing for them (described in more detail later). Of the 18, two people said that although they appreciated the care manager coming and the reassurance provided, most things were already in hand because they had been caring for the person before the hospital contact. The remaining 16 carers were able to identify other support provided by the pilot service.

One 79-year-old woman was caring for her elderly husband who suffered from hardening of the arteries and a history of falls. She reported that the care manager had met her once in hospital and had then carried out three home visits. The care manager had arranged a range of support services including the Emergency Back-Up Scheme, support from ICAST, carers from Age Concern for the initial few weeks after discharge (discontinued because her husband preferred to wash himself), and Crossroads, which allows her to go out shopping without worrying about her husband having a fall when she is not there. The Care Manager also arranged someone to come and fill in forms for Attendance Allowance, which had since been approved.

A variety of supports were mentioned by carers (see Table 8 below) as having been provided by the pilot service. Often carers’ comments were rather general and referred to the care manager providing ‘information’ or telling them ‘what was available’, while in other cases they were able to name specific services that were discussed.

Table 8: Types of supports provided by pilot service

<table>
<thead>
<tr>
<th>Type of support</th>
<th>Number of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provided information about what was available/leaflets/contact numbers/got in</td>
<td>15</td>
</tr>
<tr>
<td>touch with people/chased things up</td>
<td></td>
</tr>
<tr>
<td>Reassurance; someone to call if need help</td>
<td>14</td>
</tr>
<tr>
<td>Finance (attendance allowance; carers grants; sorting out problems with care</td>
<td>10</td>
</tr>
<tr>
<td>home fees; easing financial worry by clarifying rule for care fees)</td>
<td></td>
</tr>
<tr>
<td>Discussed or helped arrange Crossroads, befriender or sitting service</td>
<td>8</td>
</tr>
<tr>
<td>Arranged emergency back-up scheme</td>
<td>7</td>
</tr>
<tr>
<td>Discussed or helped arrange respite care</td>
<td>6</td>
</tr>
<tr>
<td>Arranged home carers or increased care package or chased up care agency</td>
<td>6</td>
</tr>
<tr>
<td>Recognised carer’s needs and well-being</td>
<td>5</td>
</tr>
<tr>
<td>Helped get disability aids (bed; rails; raised toilet seat; bath chair)</td>
<td>4</td>
</tr>
<tr>
<td>Arranged overnight care when carer in hospital</td>
<td>2</td>
</tr>
<tr>
<td>Arranged district nurse</td>
<td>1</td>
</tr>
<tr>
<td>Arranged Meals on Wheels</td>
<td>1</td>
</tr>
<tr>
<td>Arranged physiotherapist</td>
<td>1</td>
</tr>
<tr>
<td>Discussed carer support group which carer now attends</td>
<td>1</td>
</tr>
<tr>
<td>Referred to day care</td>
<td>1</td>
</tr>
<tr>
<td>Help with cleaning</td>
<td>1</td>
</tr>
<tr>
<td>Help on ward (communication with staff; found someone to help with toilet)</td>
<td>1</td>
</tr>
</tbody>
</table>
Fifteen people talked in a general way about the care manager providing information and making connections with services:

“S/he got us in touch with some different people (shows leaflets to interviewer). Crossroads, ICAST, Age Concern.”
“S/he just talked about what I needed when dad was coming out. S/he told me what I could have and what I couldn’t have. S/he’s brilliant, a lovely person.”

Fourteen carers said they thought the care manager was someone they could call any time they needed help, and that this was a source of reassurance:

“I feel that even now I could phone him/her at a moment’s notice if I needed him/her. I can’t fault him/her at all.”
“Knowing s/he is there gives me a lot of confidence to know there’s someone there who will listen to you.”

Ten people described the care manager as providing help with financial matters - securing carers’ grants, arranging help to apply for attendance allowance, or answering questions.

“S/he tried to get everything for me through the carer’s allowance. S/he wanted to help me get all that. S/he said I will sort it all out for you.”
“I got a horrendous bill (from nursing home). I phoned the council and (care manager) phoned me back and visited. S/he sorted it out and got it amended.”
“S/he arranged £400 from the care fund for petrol for the year for me.”

(ii) The most useful support provided by the pilot service
Fifteen people answered the question “What was the most useful thing the pilot service did for you?” The responses are in Table 9 below (some carers giving more than one answer).

<table>
<thead>
<tr>
<th>Most useful support</th>
<th>N/carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer’s allowance; attendance allowance; carer’s grant</td>
<td>4</td>
</tr>
<tr>
<td>Knowledge that they are there; someone to go to for information</td>
<td>3</td>
</tr>
<tr>
<td>Emergency Back-Up Scheme</td>
<td>2</td>
</tr>
<tr>
<td>Crossroads</td>
<td>2</td>
</tr>
<tr>
<td>Disability aids</td>
<td>2</td>
</tr>
<tr>
<td>Care home when carer in hospital</td>
<td>1</td>
</tr>
<tr>
<td>Getting me into the system/getting things moving</td>
<td>1</td>
</tr>
<tr>
<td>Day centre</td>
<td>1</td>
</tr>
<tr>
<td>Home carers</td>
<td>1</td>
</tr>
<tr>
<td>Bed sensor</td>
<td>1</td>
</tr>
<tr>
<td>Alarm</td>
<td>1</td>
</tr>
<tr>
<td>Carer’s card</td>
<td>1</td>
</tr>
<tr>
<td>Information on what is available</td>
<td>1</td>
</tr>
<tr>
<td>District nurse</td>
<td>1</td>
</tr>
<tr>
<td>Respite care</td>
<td>1</td>
</tr>
</tbody>
</table>
Sometimes the support provided went beyond what carers had expected or thought might be possible.

One 82-year-old carer of an elderly husband with dementia described the project worker as always making a point of coming to see them when he was in hospital. The carer found the doctors too busy to speak to her, and so would ask the care manager, who would get the information from the doctors. After discharge, the care manager arranged for day care for her husband, which allows her to go and see a sick relative, go shopping and go to the hairdressers. The care manager also arranged home carers to visit twice a day to help her husband dressing and getting ready for bed. Visits from a befriender were also arranged, but the carer had decided to stop these because of the expense. She reported that the most useful things the service did were to organise day care and home carers, because ‘it’s very tiring sometimes.’ This carer commented: ‘It’s marvellous to get that support. because I’d never heard of it’.

(iii) Evaluations of the pilot service and the care managers
Most people described the care managers in positive terms. Six people described the care manager as helpful:

“(The care manager) was proactive ... s/he really did try .... s/he has been a highlight ... has helped me more than anyone”

“(The care manager) was very helpful ... gave us the advice that I asked for..... always made a point of coming to see us when we were there (hospital)”

Ten described a variety of other positive qualities of the care manager, including having a nice personality, being sympathetic, and doing what they said they were going to do:

“S/he was very nice and I felt I had his/her support.”

“S/he was excellent. S/he tells you what’s going to happen and who s/he’s going to contact. No fuss. Within a week you get contacts coming to see you.”

“S/he’s fantastic. S/he does it straight away. Very caring.”

As mentioned above, the fact that the care manager provided reassurance and was a person that the carer felt they could call at any time should they need help or advice was particularly valued.

“S/he’s showed s/he’s there if I ever want back up and I’m very appreciative. S/he gave me the impression that if there’s anything I can do, I’m there. That was more helpful than anything else”

Carers also had a range of general positive comments about the pilot service:

“(care manager) has been a highlight and they must increase that role, certainly not do away with it. It’s not been perfect, but s/he has helped me more than anyone.”

“I’ve been happy with everything that’s happened so far.”
“I thought it was a good service.”

“It shows that people care. I get really fed up. It’s nice to know people like you and (care manager) are there. You don’t realize this when you’re in good health. All you think about is the doctor, one person, and yet there’s hundred out there to help you.”

(iv) Criticisms of the pilot service
Two carers stated that the pilot service had done nothing for them. One said that the carer’s assessment was a detailed document that did not lead to anything. In his case, the services recommended did not work out. The carer complained that there was no follow-up to the original assessment, and thought that was the end of their involvement. This person felt that someone should have got back in touch with him to monitor the situation.

“It’s (carer’s assessment) a lovely piece of paper in great detail. They’ve done the assessment and filled in boxes and scored me according to their scores, but as a working document it is no use. It became a historical document because no one has been in contact with me, or a follow-up assessment. …. I felt that was the end. That was their job. There is nobody to go to. …I appreciate there’s a lot of carers out there, and the work is very involved, so it may not be possible for a long-term support, but I think someone should have been monitoring me for the first 1-3 months and then given information on how to get back in touch after discharge.”

One carer was extremely concerned about an attendance allowance form he had filled in several times. He said the care manager had done nothing, although he did admit he could not remember anything about the contact:

“I don’t know what service s/he did. I can’t remember. I’ve had so much on my bloody plate. It’s so frustrating. I’m like a pig in a round hole.”

Five carers were happy with the service overall but had minor complaints:

• One person said that the care manager had gaps in their knowledge.
• One carer said that their carer’s assessment was wrong and that they had been given incorrect information about the cost of day care.
• Three carers said that the care manager was going to arrange something but that they had not heard anything about it since. It is important to note that this might be a timing issue, as in two cases the carers were not sure if it was still being sorted out. One carer said that the care manager said they would try and get them home visits from nurse at GP surgery but that nothing had happened; another said she had phoned the care manager about mistakes on her carers assessment, and the care manager had said she would correct it and send it back but had not; another said that the care manager was going to arrange a different zimmer frame but this had not arrived.
• Finally, one carer said there were communication problems, and that she had tried to phone the care manager a number of times.
(c) Outstanding needs and non-uptake of services

(i) Outstanding care needs
Carers were asked if there were any supports they would like, or anything that might help them in their caring role. They also described supports that they had discussed with the care manager but which had either not been taken up, were not available, or had been taken and subsequently dropped. Since all had been discharged from the carer support service, these are needs that were not satisfied by the service (for a variety of reasons – see below), things that might have been helpful, or issues that had arisen after contact with the service ended. However, they provide a number of insights into how carer support services might be improved.

When asked if there was anything that would help them in their role, three of the twenty said that they could think of nothing they needed:

“No. Anything I would like I ask someone and somebody finds it. The welfare system works beautifully in this house.”

Two people did not identify anything they needed, but it was clear from their responses to other questions that they were finding it difficult to cope and could have benefited from extra support. One man (mentioned in the last section) complained bitterly about a form from the Work and Pensions Agency that he could not fill in and that had been returned three times to him. Although the researcher suggested this was something the care manager could assist with, the man refused to accept that this was possible.

“But they are asking me and I can’t answer the questions. They’ve got to go to the people who deal with them. I don’t know the answers, I don’t know what medicines she takes.”

Another man in his eighties, whose partner had died since contact with the service, and who had a range of health problems himself, appeared to be under a great deal of stress:

“So much has gone on in the last few months, it’s been awful. To sort out everything has been really hard-going. You look for letters and they haven’t even got a date to quote. It’s been really, really difficult. ...I needed to be looking after my own health. After you lose your partner you have all the stress of the funeral and the relatives coming down. You have to put them up. And the will.... It’s a lot of work. You could do without all the stress and just deal with the situation.”

Nine carers identified a variety of things that would help them in their role. Some of these were discussed with the care manager but were not currently being received. These are presented in Table 10.
Table 10: Needs and additional supports that carers said would help them

<table>
<thead>
<tr>
<th>No of carers</th>
<th>Type of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Respite break/holiday</td>
</tr>
<tr>
<td>3</td>
<td>Day centre/befriender to allow carer free time during day</td>
</tr>
<tr>
<td>2</td>
<td>Wanted help because felt stressed but did not know what type of help</td>
</tr>
</tbody>
</table>

1
- Affordable night-time care
- Help with cooking and cleaning
- Emotional support/counselling
- Attendance/carers’s allowance even when the carer is in work
- Help with costs of transport when the cared-for person is in hospital and the carer’s health means they need to take a taxi
- Change of accommodation for the cared-for person which would include 2 bedrooms to allow the carer to stay the night
- Bigger house so that night-time carer had a bedroom
- Home visits from the GP practice nurse for the carer

(ii) Reasons why needs identified in interview or with care manager were outstanding

When carers identified supports they thought would help them, reasons why they had not transpired were often given (see Table 11). In some cases, these needs had arisen or become apparent after contact with the pilot service ceased. In other cases, the carer had not discussed the issues with the care manager. Some supports and services were identified with the care manager as helpful, but the carer was not currently receiving them. In these cases, the care manager had provided contact information, had helped set up or referred them to relevant services, but they had not been taken up, had fallen through, or had been tried and then discontinued. Interestingly, the carer often did not mention these in the interview when asked if there was anything that could help them. In some cases, the carer seemed to have given up on these supports because they were seen as impossible, unavailable or of inadequate quality.

Table 11: Reasons services cancelled or not being used

<table>
<thead>
<tr>
<th>Reason</th>
<th>No. of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cared-for person would not accept the service</td>
<td>8</td>
</tr>
<tr>
<td>Service not available or support promised but did not happen</td>
<td>6</td>
</tr>
<tr>
<td>Too costly</td>
<td>6</td>
</tr>
<tr>
<td>Service inconvenient or of poor quality</td>
<td>4</td>
</tr>
<tr>
<td>Carer does not like strangers in the house</td>
<td>3</td>
</tr>
<tr>
<td>Carer is too busy to take up the services</td>
<td>2</td>
</tr>
</tbody>
</table>

When discussing respite care, day-centres, befrienders, or sitting services, eight carers said that the cared-for person would not accept the service:

“I wonder if she’d be better in a rest home for a few weeks. She doesn’t want to go and I don’t want her to go but I wonder if it would do her good. I want to do more but there’s nothing I can do.”
“S/he did explain about Crossroads and the lady did come and did an assessment but my husband’s not happy about having strangers in the house when I’m not here ... He can’t see where they’re going.”

“No, he won’t stand for it and I’ll end up getting told off. It’s just not worth it. I wish there was, but no.”

Four people said that services suggested or that they were referred to or recommended were unavailable. One man in particular had three services recommended but all were unavailable. Two people were not receiving support from Crossroads, one because they were on a waiting list and another because the volunteer came once and did not return. In one other case, a befriending service was not being used because the carer’s mother wanted to go on trips that the service did not support:

“They’re quite picky if you’re only paying contributions. They don’t take people to the pub.”

In two cases, something promised by the care manager had not materialized (a different zimmer frame and home visits by the GP practice nurse – both described above). The carers did not know why, or whether it was still in the process of being arranged.

Six people had discontinued services, or not taken them up, because of the cost. This included the expenses of a volunteer, respite/carer breaks, home carers and a day centre. For example, one woman talking about a day centre that her husband was attending, said:

“Then I got a letter on Saturday saying it will be £22 more per week. I can’t afford it and had to cancel it. That’s a big amount when you’re on a pension. So I phoned up and cancelled it.”

Four people described services as not being adequate. One visited a rest home but did not like it, whilst two discontinued home carers because of the cost and because they never knew when the carer was going to arrive. One carer described one good carer and a string of bad experiences with carers who he felt did not have a suitable caring attitude:

“They sent out a guy who didn’t talk to my mum... he wrote in the book that he’d been in here for 7 minutes. And on one occasion I waited in the bedroom and he hardly said anything to my mum for 20 minutes. I heard her ask for a cup of tea. He hadn’t even offered her a cup of tea. ... The agency were doing things like not turning up, being 2 hours late. One Sunday I came about 2, no one had been. There should have been 2 calls by 2 o’clock. I called them up. They said we’re very short-staffed and we know you go in on Sunday. ... One was authoritative and quite scary; others hardly speak the language. There was an eastern European guy you just couldn’t understand and he would get annoyed because he’d keep repeating himself.”

Three carers described not wanting carers in their house:
“There’s nothing worse than someone in your house. You don’t want someone in your house asking you questions.”

Two men caring for their wives talked about wanting help to cope, but not knowing how they could be helped:

“Many times I could scream my head off and I wish I could get some help. But I don’t know what help I want.”

Two carers said that they didn’t ask anyone for help. One person, talking about taxi costs to visit his wife in hospital, didn’t ask because he assumed it would not be possible. Another person, who was suffering the bereavement of his partner, didn’t ask for more support either before or after the death. He described how he had found it difficult to cope and to manage his own health problems:

“I really wanted a carer to look after him but I didn’t ask (care manager). I just said I didn’t want to be a carer. (Why didn’t you ask?) That’s just me. But I’m too independent to ask for help.”

Other reasons identified were that the cared-for person was not well enough (two people), the carer did not believe the service could help (filling in an Attendance Allowance form), the carer enjoyed the person’s company and would be lonely without them, and the carer believing simply ‘I couldn’t leave him.’

(d) Experiences of hospital

Carers talked about their hospital experiences when asked whether they had felt respected and listened to while the cared-for person (or themselves) were in hospital. They were also asked about the information and support they were given at hospital. Descriptions also arose in other parts of the interviews, as carers described how they had come into contact with the pilot service.

Four people described their experiences in hospital positively:

“The ward staff were brilliant. Treated me just like one of the family. I suppose when someone’s a real carer, which by default I am, they do think of you as one of themselves.”

“They were very aware of what was going on at home, with mum’s medical condition. They all seemed to know; it had been discussed. I asked them to notify me if anything happened at night. Everyone was doing it through me which mum was happy with as she wasn’t coping.”

However, 13 recounted unsatisfactory experiences in hospital. For some, only negative experiences were described. For others, the stories were mixed – they described some wards as good and others as bad, or some staff as helpful and others as not. Problems included:
• Staff being too busy to talk to or to ask questions (6 people);
• Not being able to find anyone to help e.g. to the toilet (5 people);
• Staff not reading information that the carer had provided about medication or not listening to carer when providing information (3 people);
• Things that had been promised not happening e.g. tests, ward transfers (2 people);
• Information not being provided (2 people);
• Poor communication between services e.g. hospital and GP (2 people);
• Other (2 people).

“You never saw anybody unless they wanted to ask you a question. They were always busy when I visited. He lost his underwear and we couldn’t find anyone to ask. I just gave up. They weren’t around. They were too busy with other patients.”

“I found that a bit disturbing, not that I was worried about it, but I would have liked to know what was going to happen to her. I don’t think I was told why she was in hospital.... They don’t have much time. They’re so busy.”

“It was an awful job to get them to bring a commode. They were too busy. There didn’t seem to be any urgency. At times she was quite distressed when she needed to go to the toilet. They’re so busy, it’s a very difficult job they’ve got. They either wouldn’t or couldn’t or didn’t. They don’t seem to have the time. I got it myself and pulled the curtains round and put her on it. The nurse told me I shouldn’t do it. Which is fair enough but we had to do it because the nurses weren’t able to do it.”

“In the past, when I had a job, I put a list of pills in her handbag, so if she went into hospital they would know. We give the ambulance a list of pills but they don’t read it. They insist on asking the patient. The patient won’t always remember. ... Mum had lots of pills in the past that had side-effects or caused her problems. If you prescribe her a pill we know is unsuitable there’s no point prescribing it. A&E don’t have access to GP records. There’s no continuity about medical information throughout the whole system.”

(e) Other complaints and suggestions about support services

During the interviews, carers raised a number of concerns and made suggestions about how services might support them better. Most of these are described above concerning hospital experiences, reasons why services were not accessed, and some dissatisfactions with the pilot project. However, there were additional comments concerning services the carer was currently in contact with.

Four carers talked about problems with the discharge process. It was not clear whether the pilot project was involved at this stage. One talked about the large number of home assessments that happened all at once after discharge. Two said that they were asked about what support they needed before discharge when they didn’t really know what was going to happen or what they would need. One carer complained about not knowing who was in charge of the discharge process and that it happened with 20 minutes notice, whilst another felt the process was intimidating.
A man of 90 whose wife was now living in a nursing home, appeared angry and stressed by his experience, and occasionally became tearful during the interview. His complaints centred around difficulties getting help filling in an attendance allowance form which had been returned to him three times (mentioned above). He had found it difficult to get help, although this was not something he believed the care manager could support him with. This man described the discharge process as being aversive: “They scared the lights out of me. I went for a meeting with the social workers. Into a room with six women in front of me all asking questions about can I have her at home. There was no way she could come home because she couldn’t get upstairs to the toilet and bathroom and she was so weak on her legs she couldn’t do it. I sat in this room and when I came out I broke down. To have six women in front of you all asking questions. ... I’m 90. I’m in no state to care

Three carers talked about the income rules before you qualify for free services being unfair on those who work or who have money. Two carers talked about the difficulties of booking respite care, and suggested a more central system – one suggested a single book with all the information instead of receiving multiple leaflets. Another suggested a central service or internet site where you could see what respite care was available for what dates, and where you could make the booking on-line instead of having to ring around every home individually:

“All you get is booklet and you’re told they can’t make recommendations or give you help in telling you where vacancies are. If you’re below the income level £26,000 savings they phone you up all the time saying there’s a vacancy here. They’re more amenable to doing it. It would be nice if there was a scheme where I could say I need 2 weeks in November. What is available? A lot of homes have contracts with the local authority or the NHS to put aside beds for patients from them. Even though they have empty beds they won’t allow me to bid for beds. At the moment there seems to be no beds for respite in this area at all. I’ve just done a ring around for end of November and I’m told everywhere is full.... A telephone scheme would make life much easier, some central point or web-page which says which homes are available and when”

Two carers talked about ambulances and problems in not knowing when they would arrive, sometimes leaving them waiting for hours. One, however, said ‘But they can’t help it.”

Five carers had complaints about home care-workers and the care agencies. These revolved around a lack of continuity, unreliable time-keeping, lack of effort, and not arriving at all. Illustrative quotes are given above (in “Outstanding needs”).

A variety of other complaints were also expressed. One carer reported that her mother needed a day centre for people who wanted more mental stimulation and were more active, but that such centres did not exist in the local area. She also reported getting very tired because her mother often gets up a night, but that there didn’t seem to be any provision for night-time care that wasn’t expensive. One man had a history of unsatisfactory contact with support services:
One 52-year-old man described the care manager as having “helped me more than anyone.” However, he described becoming depressed, tired, isolated, and his life as having been taken over. This carer had a history of difficult encounters with a range of support professionals and agencies. He described becoming desperate, and services then deciding he was a problem: “Very often it falls to one person so that one person gets isolated and ill, and also gets blocked by the system …you end up being quite aggressive or just desperate. It’s quite interesting that you can be in that loop and you get referred around and around.” Later he said: “they try and make you the problem. And it’s a self-fulfilling problem that because when you’re so frustrated you perhaps become a problem. Yeah, I am a problem for them but I only want what’s right for my mum.”

3.6 Carers receiving input but not in formal evaluation: telephone interviews

The data analysed so far involved those carers who had carers’ assessments and consented to take part in the evaluation study. However, there were a significant number of carers who did not have carers’ assessments, or who were not invited to participate in the study because the care manager did not think it was appropriate, or who declined to be involved in the Carer Wellbeing Scale part of the evaluation. These carers did, however, receive support from the pilot service. In order to gain a picture of what these carers thought about the service, one of the pilot project care managers conducted telephone interviews with a small sample. This was not part of the original evaluation plans, but was considered by the steering group to be useful addition to the process. Although the involvement of the care manager was likely to render any potential criticisms more difficult for carers to make, the data do, however, give a more complete picture of the support the service offered to those not involved in the full evaluation.

In all, 15 carers were contacted. Four declined to participate, and two could not remember anything about the contact. Nine carers verbally consented to the interview and answered the questions, but only six returned their signed consent sheets. The analysis represents the responses from these six people.

The sample included three woman and three men, aged between 66 and 82 (mean = 74). Carers were asked whether there were any positive or negative changes in their situation, about the extent to which the project contributed to these changes, and what they thought of the service provided.

Overall, four carers reported positive changes in terms of receiving extra support (e.g. from Age Concern, day hospital, home carers). One carer said “You’ve made me see I don’t have to struggle and it’s about quality of life.”

Two carers reported no positive changes. Both these carers were waiting for services to start: “Everything has fallen a bit flat and things are still going through. I’m sick of waiting”. Both of these carers reported negative changes since their contact with the pilot project. One said that her husband had been moved to another town and it was a long journey for her to visit, the other reported that the home carers’ visits were “in and out. I don’t want to pay for a service she’s not getting”. The other four carers reported no negative changes.
Comments on the pilot project were positive. Two carers described it as “very helpful”, while a third said:

“Very good, excellent. I did not know where to go or who to turn to but you have been a great help and I found out lots. … You were there when I needed you.”

Another carer contrasted the service with other professionals who were not so good:

“It’s been marvellous. I’ve had experience of social workers in the hospital before and some people don’t know their jobs and I have been misinformed. Without you pulling people together me and my husband would still be in the same mess and it’s such a relief.”

This carer felt that she was now getting a much better service than she had been receiving before:

“10 out of 10. You have taken things up and followed them through. People should not have to suffer and my husband has not been getting the attention he deserves. Things are now happening for us and we can look forward to Christmas with our family.”

One of the carers who reported that the service had been helpful, also said “I appreciated the service at the time but now it feels like everything has fizzled out.”

The two carers who reported that they were still waiting for services to be delivered were more guarded in their evaluations:

“You did your work – it’s the others I’m not happy with.”

“Well, she’s on the care list now so I suppose that’s changed.”

When asked about the pilot service, this carer said: “No comment”.

3.7 Discharge team’s perceptions at Time 1 and Time 2

Discharge coordinators, whose role includes facilitating the identification of patients who may need extra support when they go home, and ensuring that patients and their families are happy with discharge arrangements, were seen by the key stakeholders as key figures in raising the profile of carers’ needs and taking carers’ experience into account during discharge processes. It should be noted that this section refers to the Discharge Team of Discharge Nurses, which is separate to the Integrated Discharge Team. Two focus groups were held with members of the hospital discharge team, one during the initial stages, and one shortly after the end of the project. The first group consisted of five discharge nurses including the team manager. The second group consisted of three discharge nurses, including the team manager and one new member of the team who had taken up role since the first group.
3.7.1 Time 1

The discharge coordinators themselves revealed that a high proportion of the cases they become involved with, perhaps 50%, require over an hour’s worth of discussion with and/or support to family members, with a major family concern arising in perhaps 2 or 3 cases per week for any one member of staff. Family involvement is identified from either meeting family during ward visits or from information from the patient and/or calling the next of kin to find out more about the home situation; other ward staff may also call them in.

The team reported that conflicts with family are quite frequent, typically centring around unrealistic expectations about rehabilitation, or the level of independence and safety of the patient after discharge. Discharge coordinators see their role as advocating for the patient, focusing on their wishes in situations where there may be a disagreement between the patient and a carer; the work with the family can often be around encouragement to accept what the family may see as an unsafe/risky decision on the part of the patient, and perhaps ensuring that “family can be family” rather than feeling they have to be carers.

The team reported that the most effective strategies for work with carers where there is a conflict are having time to talk, providing a single contact point and giving explanations about what can seem conflicting and confusing messages from other staff. Explaining what is happening can reduce anxiety and increase understanding of the process. “We make time to speak to families; it makes a lot of difference”.

In a small proportion of cases the patient reports that they have caring support from family (or friends) and a check by the team has revealed that this is either not true or not sustainable and/or safe. Here the team can find that the carers are actually relieved about the patient’s admission to hospital because of the break it gives them in their caring role.

Despite their engagement with carers, discharge coordinators were not initially familiar with the term “carers as care partners”. In discussion they recognised the principle that carers can have a role that is intrinsically linked with the patient’s care and the need to ensure that the carer is able to stay healthy and well, reporting that all people involved in the case are viewed “in totality”.

Where carers were identified as having needs, or the patient as having unrealistic expectations, the coordinators viewed it as the ward staff responsibility to contact social work; they recognised that high levels of confidence in carers’ abilities may militate against referral for support.

In relation to the pilot project, discharge coordinators did not have sufficient information to support any particular expectations; they also reported a lack of clarity on when they should be referring to the pilot, believing that such referral was perhaps more the responsibility of ward staff. But they recognised the benefits of supporting carers, in particular in helping them negotiate the range of issues around caring such as entitlement to welfare benefits: “It’s a bit of minefield out there, so people have said, when you are trying to be a carer”, and imagined that the pilot service would be able to provide substantially more time and support to carers.
3.7.2 Time 2

After the end of the project, participants in the focus group reported that not much had changed in their role with respect to carers, and that their primary role was with the patient. However, they did add the importance of consulting with family members to get “the bigger picture”. Faced with “a big rush to get people out and free up the beds”, the team saw themselves as intervening when information from family-members/carers suggested this was not advisable. One team member gave the example of a man who was about to be discharged. She phoned his son who indicated he wasn’t really coping, and wasn’t getting enough support. Feeling that the father would just end up back in hospital, she made sure the discharge was delayed.

It was also reported that getting carers’ views was important because the discharge coordinators often received mixed messages – where, for example the daughters of a man in hospital reported that their mother (the carer) was not coping, while the mother reported that although she needed some help, she did want her husband to come home. They also reported that “quite often people aren’t sure themselves which way they want the situation to go”.

The team did not routinely contact carers – only when the case was complex and there wasn’t enough information in the notes. Because family-members often came to visit the ward in the evenings or other times that the discharge nurses were not there, the team reported that they were reliant on the ward staff to communicate with relatives, and to refer on to social work if there were issues with carers. However, when they did notice the carer wasn’t coping, particularly in more complex cases, they would try and get some help or refer on “to whoever needs to help that person to manage their relative at home”. This referral would be to other professionals in the multi-disciplinary team, such as the social worker or occupational therapist.

Although the team was not familiar with the phrase ‘carers as care partners’, they did think the ward sees families as being partners in care. However, it was pointed out that carers could mean a lot of things, and it would depend on the level of care they were providing, the type of relationship they had, and how dependent their relative was. As one participant said: “If it’s a son looking after their mother, there’s certain things they don’t or shouldn’t be doing.”

The team saw the pilot project as being involved with carers “if someone was struggling to offer support”. The project workers were seen as offering more in-depth support to carers, having more time to do that than the discharge team, and having more of a focus on the carers than the social workers who were seen as dealing primarily with the patient. Specific areas of support mentioned were carers’ assessments, respite, financial and benefits advice, and support groups.

The team reported that they didn’t really have any contact with the project, except for a few early contacts at multi-disciplinary meetings. The team manager was involved in early management meetings about the project but was unable to attend subsequent ones due to
other work obligations. Rather, the project was seen as being connected to the social work team: “It's the social workers who did the direct referral, so no, I didn’t. But I do have cases where they did get a referral.” The general feeling was that “social workers were the people who liaised with them.” The participants reported that although there might have been a couple of cases, they could not remember referring carers directly to the project, but only via the social worker: “It’s quite unusual for us to pick the problem up without a social worker being involved anyway.”

As a result, the team did not think the project had affected their work, although they did feel the service was worthwhile: “It’s nice to be able to offer it to them. You’ve got a carer and you can see they’re struggling. It’s nice to be able to offer them something.”

Because of this lack of direct contact, the team members could not relate any examples of tensions or effective team working between their team and the pilot project, nor did they feel they had enough information to judge whether it had been successful. Carers themselves did not report contacts with the pilot project to the discharge team because the support would have been provided in the community after contact with the discharge nurses was finished.

The team did not think the project had raised their awareness of carer issues because they were all quite experienced, both in the hospital and in the community. However, it was felt that newly-qualified nurses might not consider carers as much as more experienced nurses, depending on whether it was part of their training.

In terms of obstacles the project might have faced, participants mentioned that the initial challenge would have probably been in getting known and getting people referred.

Finally, the discharge team talked about how difficult it was as a carer (“it’s the hardest job in the world”; “it can be quite lonely ... you’re imprisoned”), and that it would be nice to have someone in post permanently after the trial so that carers could be acknowledged and offered something.

3.8 Stakeholders’ experience and satisfaction

Key stakeholders (n=6) were interviewed for a second time at the end of the evaluation period, which also coincided with the ending of the pilot project. The themes reported here relate to their experience and satisfaction as matched against their expectations, reported earlier in this Findings section.

(a) Perceptions of the work undertaken by the project

The bulk of the work carried out by the project care managers was seen as having been with carers, with an overarching focus on sustaining the carer’s role. It was recognised that the population of carers has been very diverse, from those who have been providing regular and substantial care to others who were taking on a new role.
Whilst initially there was uncertainty about how whether the project care managers should work with both the carer and the cared for person in order to effect timely discharge, with time it became clearer that the best use of the project’s time was to work with the carer. This allowed for ongoing care management post-discharge, and the possibility of securing carers’ later agreement to support, the need for which had not been fully appreciated by them prior to discharge when the initial package had been offered.

There were however examples given of situations in which the carer had been the person admitted to hospital, perhaps as a result of having neglected their own health care needs, and where the carers’ care manager had become involved in facilitating emergency plans for the care-for person in their absence.

There continued, however, to be some residual concern about role blurring.

“There is some uncertainty about whether the care managers are also the key worker for the cared for person; from the perspective of carers, having a separate worker who is responsible for the carer’s assessment is seen as giving a more individualized response which is more likely to succeed in raising the profile of the carer’s needs; there are examples from elsewhere in the health and social care structure, where the same worker works with both the cared for person and carer, of the carer’s assessment being ignored, or given a much lower profile.”

Essentially, though, the care managers’ role was seen as having been, in any given situation, to focus solely on the carer’s needs, and to:

• Provide immediate information and advice about the hospital environment;
• Give emotional support in situations of distress;
• Provide a carer’s assessment if needed;
• Give information and advice;
• Refer to the community team if longer term or complex needs are identified;
• Refer other community based resources providing services and support for carers;
• Organise funding such as carers’ grant to support the carers’ involvement in leisure or educational activities

The work was seen as bridging between health and social care services, with a particular focus on facilitating the carer’s experience.

“The carers’ worker is a facilitative role which does not necessarily require a social work qualification, ... a bridge between health and social care services, looking out for the carer.”

“They take on referrals of carers in hospital discharge situations and carry out carers’ assessments which lead to support, signposting and services for carers and the people they care for.”

This was seen as distinctive from other services, whether statutory or independent.
“So the pilot project is distinctive in that it covers an area of work that, for different reasons, is not high priority for others.”

A key element was seen as being to explain how hospital services are working, in a way that takes account of the anxiety, confusion and exclusion often experienced by carers:

“There’s a huge amount of confusion about this, (the care manager can) demystify and de-confuse, explain the meaning of words, provide stability.”

“Carers’ main anxiety is not knowing what is going on; the system is not carer friendly; the finance pack is difficult to understand. Sometimes things are rushed – there are huge decisions. (The care manager) explained (things) ten times to one carer.”

“Carers don’t feel able to talk to the medical team. (The care manager) can facilitate discussion between the carer and the doctor. (The care manager) can get the doctor to explain things to carer.”

It was noted that as the project progressed, the care managers had grown into their role with carers, and had demonstrated increasing levels of confidence.

“(The care managers are) more confident about how to approach it.”

(b) Positive stakeholder evaluations of the service

(i) Positive impacts
Stakeholders saw the pilot service as having demonstrated a number of very positive impacts, both for carers themselves and for the systems surrounding hospital discharge.

Overall, for individual carers, the project’s intervention was seen highly significant.

“The carer’s assessment has an impact and can be a life changing thing.”

“Often (the care manager) has been the first person to listen to them.”

One key contribution mentioned here was to help the person understand the significance of their role as a carer, in effect assisting a transition of identity that may be far reaching for that individual, both emotionally and practically.

“It is also about raising carer awareness of the role they are in, of the support that is available for them.”

There was also a clear perception that improving support to carers had reduced the risk of the cared-for person returning to hospital. Direct evidence of this of course was difficult to secure, but stakeholders were confident that the way in which the project had worked would have the best opportunity of making a difference to the stability of discharge arrangements.
The provision of carers’ assessments in circumstance where these may not previously have been done was seen as a very positive move, and direct evidence of impact was provided through referrals to community support services of carers not previously known to those services.

“There have been at least 16 referrals ...none of these carers knew the service previously so in this respect they are all ‘hidden carers’ who may not otherwise have been able to access services.”

“The carers referred were, as a result of the referral, able to access health checks, grant funding for alternative therapies and other interventions, emotional support, access to a dementia workshop with other carers, referral to OT, access to monthly carers’ coffee morning, and advocacy.”

A further key achievement was seen as being raised awareness of carers’ needs amongst some professional colleagues. The project was seen have had an impact in relation to the social work team within the hospital, in terms of raising awareness of carers, by being there to do the assessments, and by discussing how assessments would impact on the services provided to both the carer and the cared-for person.

“Joint working with the social worker is very important. Understanding is growing among the social workers that it is useful to have another worker there focused on the carer. The carer’s care manager can take the flak from the carer sometimes, making it possible for the social worker to focus.”

There were examples of good joint working which had improved outcomes.

“There have been some very complex cases where the project care manager has worked well with the qualified workers... It does not necessarily take the pressure off the worker but it has an impact on the outcome. It also allows for the carer to have a relationship with a care manager and for the objectives of carer support to be built in while the social worker can deal with the tricky issues. It can be difficult for the worker to manage it all.”

Equally, raised awareness of carers’ roles and needs had been observed in areas of the hospital where previously no carers’ specialist had been present, such as A & E, and an observable impact had been made in relation to the Integrated Discharge Team.

“IDT have become skilled in identifying when and where there’s a carer and whether to refer. (There is now) an identified pathway out of IDT for carers.”

“The IDT have benefitted from (care manager’s) knowledge about carers, and awareness of carers and cared-for people has increased. They now have a more holistic approach to assessment, they know how to spot a carer and manage this. They know to refer to the care manager.”
Some stakeholders recognised the impact for themselves of having witnessed the project at work:

“*I’ve learnt. I am more aware of carers’ needs and pathways.*”

“*I have learnt from (care manager) about carers.*”

Links with community organisations were also seen as having been created and maintained. Some consultation had taken place by the service commissioners with community action groups, through the LINk network, at the time of developing the original bid. Once the project was in place, the care managers themselves had attended the Carer’ Forum to raise the profile of the service and to hear carers’ perspectives. In some circumstances effective liaison had had a positive impact for carers’ experience.

“There was on example of excellent liaison over one particularly difficult situation, in which the care manager was particularly responsive in going back out to offer support following contact by the carer’s support worker. This provided good continuity of service for the carer, and demonstrated good collaboration with (the community organisation).”

The perceived success of the project was in itself seen as having constituted a significant intervention in the context of service priorities and planning for the future.

“The most valuable thing has been proving carers’ issues need to be addressed separately; highlighting the massive gap where carers are not being looked after properly.”

(ii) Positive processes
Supporting these impacts were a number of features of the service which were seen as having contributed to and facilitated its success.

• **Value of being within the hospital environment**
The project’s location within the hospital environment was seen as a crucial element in its ability to build bridges for carers.

“(The service is) inside the hospital and can provide advice embedded in the hospital system.” In (another location outside the area) the carer support is based outside the hospital and they felt they had difficulty accessing carers in hospital and accessing services.”

Inside knowledge was sometimes helpful in individual cases, making the care manager’s role of linking the carer to appropriate health services more effective.

“(The care manager) knows what health teams are available and where to refer for support.”
“Community social work teams do not have the same links to multidisciplinary teams in hospital and are not as aware of systems and processes at work within health settings. They would also tend to respond to referrals at too late a stage, i.e. when the discharge process has already taken place.”

The hospital location was also seen as important in relation to identifying and responding to carers where the cared-for person may have low visibility to other services – for example because no social work involvement was necessary, or because care will be self-funded - resulting in a carer shouldering big responsibilities without being identified as needing any support.

“There are numerous carers where a social worker is not needed for the cared-for person, so who would pick that up? A carer may be providing all the care.”

An associated issue in relation to location of the service was the location of the care managers alongside colleagues, facilitating communication and exchange.

“Informal information exchange very important; (that’s the) value of working in same office area.”

“I would guard against the post not being attached to the social work team.”

• The importance of flexibility of engagement – timing and location

The benefits of being in a position to create a new service have been appreciated in terms of the flexibility the care managers have had to determine the nature and length of their own intervention. Timing was seen as a crucial element about which they could exercise judgement, in terms of both how and when the initial response to the carer should be made, and how long involvement should last, thus giving a response that is appropriate to the circumstances and personalised.

“... knowing when to start to engage with the carer. Gathering information first is very important. It’s difficult to get this sometimes; the medical status of the cared-for person is often not known and you cannot give an answer. It’s better to wait a couple of days if the carer is not in major distress.”

“(The project’s) response time is vastly different; (the care manager) can see someone within a hour and can follow them for the same amount of time as community social work.”

“(The care managers) can use judgement rather than that it being, ‘right, it’s 3 weeks so we are passing you on’. The carer could be a crucial point then.”

There is recognition though that this may be a protection arising from the project’s pilot status, and not necessarily sustainable.

“This is very service user led rather than driven by the system. It requires trust by management and would not be possible on a large scale.”
The flexibility to work outside the hospital was similarly seen as vital, particularly given the lack of facilities for privacy in the ward environment.

“Visiting people in their own home is very important; it is difficult for the carer to focus on her/his needs in hospital in the presence of the cared-for person.”

There was a commonly held view that because the care managers were able to follow people up in the community following discharge, the overall quality of social care intervention was enhanced.

At the point of referral on to other services, if this is the outcome of the care manager’s involvement, this referral is seen as being well informed from the contact that has taken place with the carer, providing a stronger platform for future work by others.

“More holistic ... when people are referred to the community team, I can give more information; I will focus on the overall situation and have a broader picture.”

This sense of freedom from some of the constraints of more established services extended to the ethos that developed of the project being able to advocate for carers with others within the council service network, in situations where carers’ voices may otherwise go unheard within the pressures of service provision.

“(It was important) to have some freedom and be slightly independent so (the care manager) can be on the carer’s side.”

• Value of relationship based intervention
Several stakeholders mentioned the importance of a personal approach to carers, contrasting this to the more mechanistic provision of telephone assessment.

“Access Point is like coming through to a call centre. (The carers’ care manager) is a single access point too, but it is a personal one.”

One care manager reported that many of the carers worked with had cried during their contact with the care manager, demonstrating the release of emotion that the personal engagement can engender.

“80% of carers have cried in talking with me. It’s pretty humbling, people’s dedication is incredible.”

(c) Areas of difficulty and disappointment
There were also seen to be areas of disappointment and difficulty.

(i) Lack of impact in relation to some objectives
It was doubted by most stakeholders whether impact on the awareness or views of ward staff/discharge coordinators had been achieved. No stakeholders were able to advance evidence of such impact, although there was a general perception that raising the profile of
services to carers generally would increase the likelihood of carers’ needs being taken on board throughout the system.

Equally, there was recognition that the project had not been able to target all potential groups who could benefit from its services.

“We could have targeted young carers and worked more on the over 60s.”

(ii) Challenging processes
Similarly, there were processes which had been experienced as challenging, by some or all stakeholders. These were not presented as linked to lack of impact in certain objectives, but were described as processes that had required special consideration during the life of the project, and which, if not resolvable, had sometimes impeded its work.

• Setting up
The setting up phase of the project had been experienced by some stakeholders as onerous, with frustration about a slow start, and some lost time in terms of meeting objectives early on. There was a perceived need for more preparatory work before the project launch; many matters had remained unresolved until well into the project’s operation.

“There was a lot of set up work to do from January.”

“Ideally this would have been an 18 month project, taking into account setting up the project, and including more admin support. We could have seen a lot more people and could have sorted out a lot before we started.”

“At the start I did not know much about it and it was not clear what the project was and how it would work. I could have been more prepared.”

It was also thought that the care managers needed more thorough grounding in the work of the units to which they were attached.

Compounding this were the demands of the evaluation. Running a pilot project which is being formally evaluated brings challenges of its own. The integration of project work with evaluation requirements was experienced as demanding and placed additional pressures on the setting up period.

Linked to how the initial phases of the project unfolded was a sense of disappointment about the project’s strategic location within the hospital environment.

“We could have done more to set it (the project) up better, to be more strategic.”

“With hindsight I would focus more on the strategy to engage the right people in the hospital in the project and in the Steering Group.”
• **Project capacity**

Lack of capacity was seen as having affected the project’s ability to fulfil all its objectives, impacting particularly upon those that did not directly concern individual carers. Available time was taken up with responding to individual carer referrals rather than being able to focus on an educational role with colleagues on wards.

> “We could have addressed multi-agency working and worked harder to engage the discharge co-ordinator team leader and her team. The discharge co-ordinators are a go-between between nurses and patients. They have not referred carers to social work unless they are for patients already known to social work. We have picked up carers’ issues but they have not come directly from the ward. We were hoping to become aware of carers from the wards even when the cared-for person was not known to social work.”

Even in relation to individual referrals, it was thought that carers would have been missed over the weekend because the service was not able to operate on the same 7 day system as other parts of the hospital.

• **Isolation**

The downside of freedom, in terms of being a new and pilot service, was seen as being isolation from established structures and mechanisms. In some respects the project care managers were quite isolated within the hospital environment, and were engaged in different work from the work of others in the teams in which they were located. Having separate lines of operational management on a day-to-day basis had to some extent added to the challenge.

This was compounded by the success of strategies to prevent them being drawn into the routine work of the teams with which they were co-located. That in itself had been recognised as a danger, and resisted, but the effect was to increase the sense of difference.

A related issue here is that ongoing management demands created by the service were additional to existing structures and arrangements, with the pilot project adding to established management workloads.

> “(Managers) have not been able to give the project as much attention or as much management time to this different kind of care manager role (as might have been liked)... it could have benefitted from more management hours behind it. With more time the ‘marketing focus’ (educative) could have been driven forward.”

• **Physical space**

Physical space remained a challenge for the duration of the project. A number of stakeholders referred to the hospital being a ‘carer unfriendly’ environment, in terms of both carers’ own experience and the profile of their presence with staff.

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12 Whilst the two care managers were line-managed by the hospital social work team manager, who was also their clinical supervisor, the daily operational management did, as a result of their placement in different teams which had different remits, come from two separate lines of management.
“In an ideal world (there would be) a carers’ room in hospital where carers can be contacted, a physical and recognisable presence for ward staff to know about and refer to.”

Sometimes this extended to workspace for the care manager.

“(We have) a very busy environment; (there is) lack of access for the care manager to adequate working space including a PC, so they had to come back over the road to the social work department.”

• Service availability
Some challenges were experienced as a result of insufficient service capacity in those services to whom the care managers were referring on following their assessment of carers’ needs. This echoed some of the comments made by carers themselves about arrangements made by the care managers which hadn’t then come to fruition. The problems related both to the range of services available and the capacity of those that did exist to respond to referrals.

• Consultation with stakeholders
There was some concern that community stakeholder consultation, particularly with carers’ themselves, might have been started earlier, before plans for how the care managers would work became too fully formed.

“It’s important to consult with local carers’ organizations at an early stage in project development and to consult with carers too about their experiences of hospital discharge and what would best help them. This should be prior to setting up any project.”

(iii) Concerns about the future
A further area of difficulty and disappointment was the future, beyond the end of the project. Concern was expressed about the follow on for carers’ services and a fear that in the face of ongoing, severe pressures to effect timely discharge, attention to carers could slip in the absence of a dedicated project.

“The staff see the benefits of carer support but there is so much pressure to do the basic assessments to get people out of hospital; we need to tackle the perception that carer’s assessments are non essential to discharge planning.”

“(Planning for discharge) would be a much longer and more in depth process than we can do most of the time. It’s not to say we put people at risk by such rapid discharge planning, but we ... don’t follow anyone once they are discharged, other community teams do.”

“I don’t know how we are going to plan for this (ending of the project and continuing the work). We need other carers’ care managers.”

Plans for changes to care pathways, to enable hospital based staff to follow people out into the community, were welcomed, with recognition that this would brings carers rather more
directly to professionals’ attention, albeit only in circumstances where the cared-for person is known to social work. Equally, however, concerns were expressed about the lack of dedicated carer staffing within plans for the new community rapid response service, resulting in reliance likely to be placed upon existing channels for accessing carers’ assessments and support.

Similar concerns about the future were expressed from community organisations.

“There is concern about what will happen without these posts, and it’s not clear whether there has been any influence in terms of getting other workers to carry out carer’s assessments; there is a clear need for carers’ care managers in hospitals – this is as important a role as in the community.”

For the future, hopes were expressed that ways could be found of preserving the focus on carers’ needs and ambitions, as a counter-balance to the rather more risk and safety-focused interventions with the cared-for person at the point of discharge. Stronger links between the hospital and carers’ organisations in the community were seen as important to this, as were ways of ensuring that responsibilities for carers’ assessments were given a higher profile once the pilot project concluded its work.

4. Conclusions and recommendations

4.1 Drawing conclusions from the range of data

Evaluating complex human services is recognised as difficult, since no single source of data is usually definitive. In order to build up a picture of service practice and effectiveness, it is necessary to collect data from multiple perspectives, including data on both outcome and process. This evaluation has collected a large amount of data, from key stakeholders, service workers, professionals in allied roles, and service-users themselves. As well as collecting data on issues of process, aims and scope, we have collected qualitative and quantitative data relating to outcomes. This has allowed us to build a rounded picture of the service.

(a) All stakeholders and all but a few carers valued the service. That there was a pre-existing need is indicated by the fact that 82% of carers reported on initial contact that they would like extra help in their caring role. The service provided a varied range of support to carers, both in the hospital and in the community, and helped carers access many services they were not previously using. These included practical help in terms of finance, registration with the Emergency Back-Up Scheme, and information about and referral to home care, respite, day care and sitting services, and to carers’ organisations in the community. The care managers also provided emotional support and recognition to carers, and the knowledge that they were there if needed provided a sense of reassurance to many carers. The number of carers’ assessments completed in the hospital context increased from approximately two in the previous year to 122, a huge increase. There was evidence that previously ‘hidden’ carers had been identified and supported.
(b) Quantitative data all supported the conclusion that the service had a positive impact. Patients were more likely to experience shorter-than-expected stays in hospital compared to than longer-than-expected stays, although interpretation of this outcome is difficult, since involving the carer and conducting a proper assessment might either lead to an increase or decrease in hospital stay, depending on the circumstances. For example, the discharge team reported that they sometimes had to delay discharge after discovering the carer was unable to cope until further support was arranged. In such cases, a longer length of stay can mean the person is better able to cope and less likely to be readmitted. In addition, care managers often had their first contact with carers after discharge, particularly given that they worked office hours and were not present at weekends or in the evenings, when carers might be more likely to visit. In a number of cases, then, care managers were not involved in the discharge process.

(c) There was a significant increase in carers’ confidence and satisfaction with their role as carers over the course of the project. Again interpretation is not straightforward as it was impossible to use a control group for comparison, but given that many patients had conditions that were likely to deteriorate, it is encouraging that carer’s wellbeing did not decline on any of the measures, and showed improvement on this one crucial dimension.

(d) The personal qualities of the care managers were an important aspect of the service, and carers often reported on how helpful, sympathetic, proactive or reliable the care managers were. However, a number of people reported problems with home carers in terms of professionalism, attitude, communication and time-keeping. In some cases this resulted in the carer cancelling the service. Some carers reported difficulties booking respite care, and suggested a central system would make the process easier.

(e) While some carers felt positively towards their caring role, a number reported suffering severe negative effects in both their mental and physical well-being. The only measure of carer health in the evaluation consisted of two short questions, which showed improvement over time that was approaching significance. Although the nature of challenges faced by carers was not the major focus of this evaluation, this did appear to be a population under a degree of stress, and support services might be expected therefore to have an impact on carers' levels of health and their own use of health services. This should be taken into account when judging the benefits of services for carers.

(f) In terms of increasing awareness of carers amongst hospital staff, key stakeholders reported that the project had made staff more aware of carer issues, particularly among hospital social workers and the integrated discharge team. There was less evidence among the discharge coordinators that the project had made any difference to their work practices but, despite having had little contact with the care managers, members of this team were very supportive and believed the role should continue. Key stakeholders suggested that due to the demands of the role in supporting individual carers, in the context of a service with limited capacity, care managers could not focus to any great extent on the educational aspect of their work. Such a role might be built in to future services for carers.
(g) The advantages of location and flexibility in the role of care managers was noted by key stakeholders, in terms of the advantage of following carers back into the community and arranging support at times most appropriate to the carers’ needs. In many cases this seemed to work well, however there were a few carers who still had outstanding needs after contact had ceased. Although this was a minority of carers, it would seem helpful to have more consistent follow-up or referral procedures on discharge, particularly since support often depended on a number of different agencies, and services could fall through for a number of reasons after contact with the care manager had ended. When this did happen, some carers seemed to have given up on these services. The majority of carers interviewed were confident they could contact the care manager at a later date, but some didn’t like to ask for help, and a very small number felt they had been discharged from the service. In these cases a more proactive approach to follow-up might be useful.

(h) In the early stages, stakeholders discussed whether the care managers would work with both the carer and the patient. Although this appears to have resolved over time, with the care managers having a clear focus on the carer, and becoming involved in cases through assessment of (or advice to) the carer, the interventions designed to support carers often involved support for the cared-for person also, and in this respect the distinction between the needs of the two parties could not really be separated. Indeed, carers themselves often saw the needs of the cared-for person entwined with their own; for example, adjusting a package of care brought benefits for both parties, as did the use of a day centre. Given the project’s ending, and the evidence here of its impact for carers, there is a need for further consideration of how the focus on carers can be maintained when discharges are more routinely being arranged by staff whose primary focus is the patient/cared-for person.

(i) Stakeholders reported the usefulness of the care managers being based in the social work team and the integrated discharge team for both parties. Limitations included the fact that care managers did not work on a 7-day basis, and that there was no dedicated space for carers in the hospital. Now that the benefits of the project had been recognised, concerns were also expressed about what would happen after the end of the project.

4.2 Recommendations

The evaluation team is aware that the pilot service will not continue in its present form, or become. It is important to state that this decision is not linked to perceptions of effectiveness, as the overall consensus is that the service has achieved on many of its objectives. The following recommendations, therefore, are designed to support further future work with carers in whatever context or organisational structure that takes place.

(a) There is strong evidence to support the value of a dedicated service for carers. A targeted approach has been shown to be very valuable in enabling priority to be given to carers’ needs in a context where other priorities might otherwise consume more attention, and in times of resource scarcity. In order to ensure that work with carers is
undertaken, legal obligations under carers’ legislation are met\(^1\), and national policy goals supported\(^2\), consideration should be given to how carers’ interests and contribution to timely discharge can be facilitated and the lessons learned from this pilot project brought forward into new service structures.

(b) Further dedicated resource is likely to be helpful in supporting a focus on carers’ needs, whether this is provided through a dedicated service or through a higher profile for work with carers in other adult social care services.

(c) It is important that services for carers are available within the hospital context. This plays an important role in bridging carers into health systems that are very unfamiliar to them, and in identifying carers of people not otherwise known to social care services, thus increasing potential for support to hidden carers.

(d) Work undertaken with carers under the auspices of one dimension of the hospital system (i.e. social care) needs to achieve a higher profile with wider hospital systems and staff groups. This requires proactive preparation at strategic and operational level in order to encourage ownership of ‘carers as care partners’ perspectives beyond the social work team, and to facilitate practical ways of enabling the work to be undertaken (for example through the provision of space and/or privacy).

(e) In identifying evidence of effectiveness in the outcomes of work with carers, it is important to build in mechanisms for tracking health and wellbeing outcomes for carers and for cared-for people; the relationship between these is complex, and simple quantitative measure, such as hospital bed occupancy of the cared for person, will not give an accurate picture of impact. It is recommended that tools for tracking health and wellbeing over time are built into assessment and reassessment schedules to facilitate the building of such an evidence base.

(f) The value of flexibility and continuity of services for carers has been demonstrated. Hospital/community services boundaries must be flexible enough for carers to experience continuity of relationship with their care manager, whether from the community into hospital or from hospital into the community.

(g) Longer term stability of services is still experienced as challenging for carers, who have concerns about quality and cost and sometimes do not know how to raise these concerns following case closure. There is a need for more robust care pathways/options at case closure to ensure that carers know where their supports may be expected to come from, how to access them and from whom, and how to raise concerns about their quality.

(h) Strong links with community organisations able to give voice to carers’ perspectives, and their early involvement in plans, at both strategic and operational level, are vital.

\(^1\) Carers (Recognition & Services) Act 1995; Carers and Disabled Children Act 2000; Carers (Equal Opportunities) Act 2004.

APPENDIX 1

Topic lists for key stakeholder interviews at Time 1 and Time 2

Time 1
1. What is your own work role?
2. Could you tell me a little about your agency’s responsibilities in relation to carers?
3. Have you been involved in the setting up of the carers’ support in hospital project or in discussions about the need for the project? If so, what is or has been your role? How and why did you get involved?
4. What is your understanding of why the project set up (i.e. what was the issue that needed to be addressed)?
5. What do you think the project is seeking to achieve?
   i. Who do you think will benefit from this pilot project and how do you think they could do so?
   ii. Are there other outcomes that you think are important for the project to demonstrate?
   iii. If there are several objectives/outcomes, how would you rank them in order of importance, and why?
6. How is the service different from what the regular hospital social work team would provide? How is it different from what a community social work team would provide? How does it differ from other (perhaps voluntary sector) services for carers?
7. Do you think the service will encounter any challenges in meeting its objectives?
8. What could help overcome those challenges?
9. How should we measure the success of the project? What would be evidence of its success, for you?

Time 2
1. What involvement have you had with the carers’ support project over the last 12 months?
2. How would you describe what the project does, what is the focus of its work (i.e. how would you describe it to someone who had no knowledge – we’re after a descriptive statement here, not an evaluative one).
3. How is the service different from what the regular hospital social work team would provide? How is it different from what a community social work team would provide? How does it differ from other (perhaps voluntary sector) services for carers?
4. Thinking back to what you hoped the project would achieve, how far have those expectations been met?
5. What impacts do you think the project has had?
6. Has anyone, or any group in particular, benefitted from the work of the project?
7. Can you give some examples of those impacts and benefits?
8. If you had to rank the project’s achievements in order of value, what would that be?
9. Are there ways in which the project has not lived up to your hopes/expectations?
10. Why do you think that might be?
11. Have there been barriers? What were they?
12. Are there things that could have been done differently, now with hindsight?
13. If you were advising someone else about setting up a similar project now, what tips would you give them?
APPENDIX 2
Topic lists for focus group with hospital discharge staff at Time 1 and Time 2

<table>
<thead>
<tr>
<th>Time 1</th>
<th>Specific issues to probe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main topic</strong></td>
<td><strong>Specific issues to probe</strong></td>
</tr>
</tbody>
</table>
| **1. Can you tell us briefly about your role in hospital discharge?** | • What is your role with staff working on the wards?  
• Are there any particular challenges in your work relating to discharge? |
| **5. Can you tell us how you get involved with the carers of people who are in hospital?** | • What kind of contact do you [and your colleagues on the wards] have with carers and why?  
• In what proportion of cases is there significant involvement of carers?  
• What are the positives and negatives of working with carers? |
| **3. What does the term “carers as care partners mean for you”?** | To what extent do your colleagues on the wards see carers as care partners? |
| **4. What do you know about the carers pilot project?** | • What do you think it is trying to achieve?  
• What kind of work will it be doing?  
• What (if anything) will it be doing that is new, or different from what you already do with carers?  
• How is it different from other services for carers that you know about? |
| **5. How do you think the carers’ project will impact upon your work and the work of staff on the wards?** | • How might it help?  
• Might it hinder in any way? |
<p>| <strong>6. Do you think the project will encounter any challenges?</strong> | • If so, how could these be overcome? |
| <strong>7. How should we measure the success of the project?</strong> | • What would you consider to be evidence of success? |</p>
<table>
<thead>
<tr>
<th><strong>Main topic</strong></th>
<th><strong>Specific issues to probe</strong></th>
</tr>
</thead>
</table>
| 1. Can you tell us how you get involved with the carers of people who are in hospital? Has it changed from the last time we spoke? | • What kind of contact do you [and your colleagues on the wards] have with carers and why?  
• In what proportion of cases is there significant involvement of carers? |
| 2. What does the term “carers as care partners” mean for you”?                | • To what extent do your colleagues on the wards see carers as care partners?            |
| 3. What do you know about the carers’ pilot project? How much contact have you had with the project workers? | • What do you think it tried to achieve?                                                   
• What kind of work did it do?                                                   
• What (if anything) did it do that was different from what you already did with carers? 
• How is it different from other services for carers?                           |
| 4. How do you think the carers’ project has affected your work and the work of staff on the wards? | • Has is changed how you work with carers?                                                 |
| 5. Last time there was a feeling that your priority was to advocate for the patient rather than the carer. I wondered if this was still the case, and how this might have affected your contact with the project? | • Have there been any examples of tensions/disagreements with the project workers?       
• Have there been any examples of good team working?                            |
| 6. Do you think the project has encountered any challenges/obstacles?         | • If so, how could these be overcome?                                                      |
| 7. Do you think the project has been successful or unsuccessful?             | • Any examples? e.g. what carers have said to you; what you have observed?                |
| 8. Are there any ways forward that you can see for working with carers?      | • Either for your team or forward staff?                                                    |
APPENDIX 3
Carers Wellbeing Schedule – Section A

A. Well-Being

The questions in Part A are about aspects of your general well-being. All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, tick one box on each line that best reflects your caring responsibilities as a whole.

Please write today’s date: __________________

Your role as a carer
The first set of questions asks about your role as a carer. (Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. not having enough time to yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. having to put the needs of the person you care for ahead of your own needs?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. not being able to take a break from caring?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. not being able to plan for the future?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Your relationship with the person you care for
The next questions are about your relationship with the person you care for. (Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. strains in your relationship with the person you care for?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. the person you care for being too dependent on you at the moment?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. the person you care for becoming too dependent on you in the future?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. the person you care for saying things that upset you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. feeling irritable with the person you care for?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. reaching ‘breaking point’, where you feel you can’t carry on with things as they are?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Your relationships with family and friends
(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. strains in your relationships with family and friends, because of your caring responsibilities?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>13. “drifting apart” from family and friends, because your caring responsibilities limit the time available to keep in contact with them?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>14. feeling isolated and lonely because of the situation you are in?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>15. not getting the support you need from family and friends?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Your financial situation
(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. your own financial situation?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>17. the financial situation of the person you care for?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Your physical health
(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. your own physical health?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>20. your caring role making your physical health worse?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Your emotional well-being
(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. being unable to cope with the “constant anxiety” of caring?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>22. feeling depressed?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>23. being unable to see anything positive in your life?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>24. lack of sleep brought about through worry or stress?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>25. lack of sleep caused by the person you care for keeping you awake at night?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>26. feeling so exhausted that you can’t function properly?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
### Stigma and discrimination

(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>27. people treating you differently because of the illness/condition of the person you care for?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### Your own safety

(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about the person you care for...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### The safety of the person you care for

(Please tick one box on each line.)

<table>
<thead>
<tr>
<th>During the past 4 weeks, how concerned were you about the person you care for...</th>
<th>A lot</th>
<th>Quite a bit</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>30. harming themselves?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>31. getting themselves into dangerous situations?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>32. relapsing or deteriorating, such that it puts their safety at risk?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
**APPENDIX 4**

**Carers’ interview schedule**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 1. | Confirmation of carer as appropriate for interview  
Please confirm:  
• Who you are  
• That you received support from the “Carer Support in Hospital” pilot project (within the sample dates)  
• The person you care for has now been discharged from hospital |
| 2. | Time since discharge  
How long has it been since the person you care for has now been discharged from hospital? |
| 3. | What the pilot service did  
Please describe exactly what the pilot service did for you |
| 4. | Caring role now  
Please tell me about how your caring role has been since the person you care was discharged from hospital?  
• What does it entail you doing for the person you care for?  
• What services have the carers support team been able to put in place for you/the person you care for?  
• What have been the most useful things they have been able to provide?  
• Are there any supports you would like that they haven’t been able to put in place?  
• Do you have support with caring from other family or friends? What form does this take?  
• How confident do you feel about the caring role you have? Do you feel able to continue it? What else would help?  
• How do you feel in yourself? What is the impact for you of caring?  
• Has the carer support project helped with how you feel, and how confident you are? How? |
| 5. | Participation with services  
Please tell me about how you have found working with others (services) in looking after for the person you care for?  
• how do you feel you were treated by the carer support project in relation to setting up the services for you? How far do you feel they took your views and feelings into account?  
• How far do other services you may be involved with take your views and feelings into account? |
| 6. | Utility of information and support in hospital  
What information and support did you get whilst the person you care for was in hospital? And how useful was this to you? |
| 7. | Recognition as ‘expert care partners’  
Please tell me about how the hospital staff treated you? How far do you feel they took your views and feelings into account? |
| 8. | Other comments  
Is there anything else about your caring role and the “Carer Support Through the Hospital Discharge Process” pilot service you would like to tell me? |
APPENDIX 5
Information and consent sheets for participants

1. Information for key stakeholders and hospital discharge staff at Time 1

“Carers’ Support in Hospital” Pilot Service: Royal Sussex County Hospital

INFORMATION ABOUT THE EVALUATION FOR STAFF MEMBERS at Time 1

A team from the University of Sussex has been asked to evaluate the Carers Support in Hospital pilot project, to see whether it is meeting its objectives of improving support to carers during the process of hospital discharge. It is important that we identify how well the service meets carers’ needs, whether it helps them to undertake their caring role, and how satisfied they are with the service. Also important are the views of professional staff associated with the project, those who work closely in hospital discharge, and others involved in working with carers. The evaluation will be used to help plan future services for carers.

The evaluation has three strands, and is taking place throughout 2010:

a) Individual interviews with key staff and managers responsible for the development, management and delivery of the project, to identify expectations and perceptions of the project’s achievements. We hope that each person will offer two interviews - one early on in the project’s operation (April 2010), and a second towards the end of the evaluation period (October or November 2010);

b) Focus groups with staff working in hospital discharge, to identify expectations and experience of the project’s contribution to the work of hospital discharge, and the extent to which carers can be viewed as ‘expert care partners’. We hope that participants will attend two focus groups - one early on in the project’s operation (April 2010), and a second towards the end of the evaluation period (October or November 2010);

c) Anonymised project information about the needs and wellbeing of carers using the project, and a follow up interview with a sample of carers once their involvement with the project has ceased.

If we approach you about taking part in an interview or a focus group, we can answer any questions you may have in order to help you decide whether to take part. If prior to then you would like further information about the evaluation, please contact Suzy Braye (s.braye@sussex.ac.uk) or Imogen Taylor (i.j.taylor@sussex.ac.uk).
Evaluation of the “Carer Support in Hospital” Pilot Project
CONSENT FORM FOR STAFF MEMBER PARTICIPATION IN AN INTERVIEW OR FOCUS GROUP

This form is to record your consent to participating in an interview or focus group with the evaluation team.

Name........................................................................................................................................

Position: ....................................................................................................................................

1. I have received the information sheet giving details of the research and I understand what the research is about. I have had the opportunity to ask questions and receive any further information I felt was necessary to help me decide whether to take part.

2. I understand that the information I give in this interview/focus group will be used only for the purposes of this research; my identity will not be revealed to anyone other than those present and the research team; I will not be named in any report or publication, although I recognise that the nature of my role may mean that comments could be traced to me by those familiar with my organisation. My personal details will be kept securely by the research team and securely destroyed once the research is completed.

3. I understand that the only exception to this confidentiality undertaking is in relation to information about likely harm to a vulnerable person, in which case I will be informed of details of any disclosure considered necessary by the research team.

4. I understand that with my agreement the interview/focus group will be recorded and if a recording is made it will only be used for the purpose of this evaluation, will be stored securely and will be disposed of at the end of the research.

5. I understand that after the interview I can view the transcript of the notes of the interview, and that I can add to or change what I wish to say, or clarify what I meant in answer to any of the questions. If I am taking part in a focus group, then I will have the opportunity to view and correct the transcript of the discussion.

6. I understand that I can ask for the interview or focus group to stop at any time, either for a break or to finish if I feel I do not want to continue. I can also at any time withdraw my permission for my comments to be used.

7. I consent to being interviewed or taking part in a focus group for this project.

Date.............. Signed..............................................
3. Information for hospital discharge focus group attendees at Time 2

“Carers’ Support in Hospital” Pilot Service: Royal Sussex County Hospital
FOLLOW UP INFORMATION ABOUT THE EVALUATION FOR STAFF INVOLVED IN HOSPITAL DISCHARGE

A team from the University of Sussex was asked to evaluate the Carers Support in Hospital pilot project, to see whether it is meeting its objectives of improving support to carers during the process of hospital discharge. The results of the evaluation will be used to help plan future services for carers.

The evaluation has had three strands, and took place throughout 2010:

a) Individual interviews with key staff and managers responsible for the development, management and delivery of the project;

b) Focus groups with staff working in hospital discharge, to identify expectations and experience of the project’s contribution to the work of hospital discharge, and the extent to which carers can be viewed as ‘expert care partners’;

c) Anonymised project information about the needs and wellbeing of carers using the project, and a follow up interview with a sample of carers.

The meeting arranged for 13th January 2011 is a follow up to the discussion that took place last May, early in the life of the project. Now that the project has completed its year of operation, we’re interested to know whether, from your perspective, the project’s work with carers has affected your discharge work on the wards.

If prior to the meeting you would like further information about the evaluation, please contact Suzy Braye (s.braye@sussex.ac.uk) or Mick Finlay (mf251@sussex.ac.uk).
4. Information and consent sheet for carers, permitting release of anonymised data to the research team

“Carers’ Support in Hospital” Pilot Service: Royal Sussex County Hospital
INFORMATION ABOUT THE EVALUATION FOR CARERS AT REFERRAL TO THE SERVICE

A team from the University of Sussex has been asked to evaluate the carers support in hospital pilot project, to see whether it is meeting its objectives of helping to improve support to carers. It is important that we identify how well the service meets your needs, whether it helps you to undertake your caring role, and how satisfied you are with the service. The information will be used to plan future services for carers in Brighton & Hove.

We know that you may have a lot on your mind when you start to use the carers support service, and for this reason we will not ask you to give us any extra information now. We would just like your permission for the support service to let us have information about your assessed needs, and about the services they provide you with. They will not give us your name, or any personal details that will identify you - everything they give us will be completely anonymous. The service you receive from them will not be affected in any way. The more carers take part in the evaluation in this way, the better able we will be to say what difference the carers support project makes. Later on, when you come to the end of your involvement with the support project we will ask you whether you would like to take part in an additional interview to tell us more about your experience; but you don’t have to decide about that now.

If you would like further information about the evaluation before deciding whether to let the project give us anonymous information about your assessment, please contact Suzy Braye, 01273 876668, s.braye@sussex.ac.uk

If you agree that the project can give us anonymous information about your assessment, please give your consent on this form and return it to your care manager, who will keep it confidentially on file.

I consent to the Carers Support Project giving anonymous information about my needs, and the services they arrange for me, to the evaluation team.

Date ………………… Signed……………………………… Name ……………………

THANKYOU from Suzy Braye, Imogen Taylor and Andy Cheng
University of Sussex Carers’ Support Project Evaluation Team
5. Information and consent sheet for carers, permitting release of name and contact details to the research team for the purpose of discussing the possibility of an interview

“Carers' Support in Hospital” Pilot Service: Royal Sussex County Hospital
FURTHER INFORMATION ABOUT THE EVALUATION FOR CARERS AT THE POINT OF CLOSURE OF THE SERVICE

You may remember that a team from the University of Sussex has been asked to evaluate the carers support in hospital pilot project, to see whether it is meeting its objectives of helping to improve support to carers. The information will be used to plan future services for carers in Brighton & Hove.

Now that you are about to or have finished using the carers support service on this occasion, we would like to invite you to meet with a member of the research team to tell us what you thought about the service, and whether it has made life easier for you.

This would involve a meeting at a place of your choice, for about an hour, and some questions about your experience, both of caring and of using the support service. Everything you say would be treated in confidence, and any comments you make would be anonymised before being used in any evaluation report. The care managers involved with the carers support service would not get to know what you personally say to the research team.

You don't have to decide now. All we need at this stage is an indication of your interest in taking part in an interview, and your permission for your care manager to pass this form to us, so that we can contact you with further information and answer any questions you may have before agreeing to take part.

I am interested in taking part in an individual interview about my experience of using the Carers Support Project, and I consent to the project giving my contact details to the evaluation team so that I can be contacted.

Date .................... Signed........................................... Name ..............................

THANKYOU from Suzy Braye, Imogen Taylor and Andy Cheng
University of Sussex Carers' Support Project Evaluation Team
6. Consent sheet for carer’s interview

“Carer Support in Hospital” Pilot Project at the Royal Sussex County Hospital

CONSENT FORM FOR CARER INTERVIEW PARTICIPATION

This form is to record your consent to participating in an interview with the evaluation team at the end of your involvement with the Carers Support Project.

Name........................................................................................................................................

8. I have received the information sheet giving details of the research and I understand what the research is about. I have had the opportunity to ask questions and receive any further information I felt was necessary to help me decide whether to take part.

9. I understand that comments I make in this interview may be set alongside earlier assessments carried out during my use of the carer support project in order to provide a rounded picture, from my own personal perspective, of my experience.

10. I understand that the information I give in this interview will be used only for the purposes of this research; my identity will not be revealed to anyone outside the research team, I will not be named in any report or publication and information that could identify me will be changed. My personal details will be kept securely by the research team and securely destroyed once the research is completed.

11. I understand that the only exception to this confidentiality undertaking is in relation to information about likely harm to a vulnerable person, in which case I will be informed of details of any disclosure considered necessary by the research team.

12. I understand that with my agreement the interview may be recorded and if a recording is made it will only be used for the purpose of this evaluation, will be stored securely and will be disposed of at the end of the research.

13. I understand that at the end of the interview, the researcher will share with me the notes he or she has made, and that I can add to or change what I wish to say, or clarify what I meant in answer to any of the questions.

14. I understand that I can ask for the interview to stop at any time, either for a break or to finish if I feel I do not want to continue. I can also at any time withdraw my permission for my comments to be used.

15. I consent to being interviewed for this project.

Date............... Signed........................................
7. Consent sheet for telephone follow up by carer’s care manager with carers not participating in the formal evaluation

“Carers’ Support in Hospital” Pilot Service: Royal Sussex County Hospital

As I explained when we spoke on the phone, a team from the University of Sussex is evaluating the Carers Support in Hospital Pilot Project, to see whether it is helping to improve support to carers.

You kindly gave me your views about the service, and you agreed to allow me to pass your views on to the evaluation team. This consent sheet merely records your agreement. Once you sign and return it to me, I can then make sure that your views are passed into the evaluation. Of course I will not be releasing your name and address, or any personal details that could identify you, so your views will be given completely anonymously.

If you agree that I can pass your views to the evaluation team, please give your consent on this form and return it to me in the stamped addressed envelope enclosed.

I consent to the Carers Support Project giving anonymous information about my needs, and the services they arrange for me, to the evaluation team.

Date ………………… Signed……………………………… Name ……………………

Many thanks indeed
Care Manager: Carers Support in Hospital Project