The Princess Royal Trust for Carers ‘Out of Hospital’ Project – Learning from the Pilot Projects

Final Report – May 2010
Acton Shapiro

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Acknowledgement

The Out of Hospital Project, funded by GSK, started in 2006/2007 and this report is based on the work undertaken during the second and third years of the project. Ultimately, the Out of Hospital Project aims to highlight ways in which supporting carers at the point of hospital discharge and afterwards can save time and money through avoiding unnecessary hospital admission, saving on medication bills and improving the health of carers.
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Abbreviation List

CHDC  Carers’ Hospital Discharge Coordinator
CHLW  Carers’ Hospital Liaison Worker
COPD  Chronic Obstructive Pulmonary Disease
CQC   Care Quality Commission
DDN   Deputy Director of Nursing
DH    Department of Health
GWH   Great Western Hospital
IHD   Ischaemic Heart Disease
PCT   Primary Care Trust

The vision of The Princess Royal Trust for Carers is to meet the diverse needs of carers through excellent local and national services. Through a unique network of 144 independently managed Carers’ Centres, 85 young carers’ services and interactive websites (www.carers.org and www.youngcarers.net) the Trust and the Centres it partners together provide quality information, advice and support to over 400,000 carers, including approximately 25,000 young carers.

In 2006 GlaxoSmithKline awarded funding to The Princess Royal Trust for Carers which has supported two independent Carers Centres in developing and delivering pilot projects aimed to improve carer experiences of the hospital discharge process.

This report evaluates the work of those projects and highlights project learning.
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Key Messages

This section draws together the key messages from the whole study and groups them for the four main audiences for the research. The key messages highlight practical ways to support carers at the point of hospital discharge and afterwards, with the aims of saving time and money through avoiding unnecessary hospital admission, saving on medication bills and improving the health of carers.

The messages are divided in terms of audience but the approach is holistic. Policy makers, PCTs, hospital trusts and carers’ organisations can work with carers to change systems and attitudes and create together a local health service which benefits patients and their families by recognising the role of carers and supporting carers’ choices as partners in care.

Key Messages for Policy Makers

Hospital trusts have many priorities, all competing for staff time and resources. Unless there is a clear requirement for hospital trusts to address the issue of recognition and support for carers around the time of discharge, progress in improving carers’ experiences of discharge will remain slow. Four things could begin to make a difference:

- A requirement by the Care Quality Commission for hospital trusts to identify all carers, not just those of people with a learning disability
- An even stronger emphasis on carers in Department of Health guidance on hospital discharge
- Raising recognition and support for carers to a Tier 2 priority in the NHS Operating Framework.
- A commitment to strengthen the evidence base relating to the effect of carer support around hospital discharge on NHS budgets and services.

Key Messages for Hospital Trusts

A high level of carer awareness amongst hospital staff is vital if carers are to be recognised and involved in the discharge process. To achieve this, hospital trusts should consider:

- identifying a Carers’ Champion at executive level who can promote understanding and support for carers’ issues at a high level within the hospital trust and has the status to manage the development and implementation of hospital discharge policies and procedures relating to carers (ideally this role would be supported by a hospital trust-wide group with a remit to improve services for carers)
- establishing carers leads on all wards and departments, with a clear remit to promote the recognition of carers amongst colleagues
- incorporating information about carers (including a definition of the term ‘carer’) into staff induction training/induction packs
- taking steps (e.g. include reference to family carers in patient information or display information for carer on wards) to encourage carers to identify themselves to ward staff.
Carer awareness needs to be supported by policies and procedures which emphasise the importance of involving carers in the discharge process, acknowledge their needs and rights and enable staff to record carer details. As a minimum there should be:

- clear reference to the identification, recording and referral of carers in the hospital discharge policy
- questions designed to encourage the recognition of carers built into core systems (whether paper or electronic) such as admission and assessment processes
- nursing information systems should have a clear place to record carers’ details which enables staff to distinguish between ‘next of kin’ and a family member or friend who has caring responsibilities.

There is also a need for a commitment to gathering clinical audit data on the numbers of carers with which the hospital trust comes into contact, how many get support, whether those who get support appear to have relatives who experience better discharges and whether hospitals achieve efficiencies.

**Key Messages for PCTs**

Through their commissioning work PCTs can play a vital role in encouraging, even requiring, hospital trusts to take steps to recognise and support carers. They should consider:

- agreeing ‘carers’ standards’ within the contract with hospital trusts which they expect those hospital trusts to meet
- requiring hospital trusts to have a carers’ charter which sets out the hospital’s responsibilities to carers and is publicly available
- encouraging hospital trusts to actively participate in wider strategic and developmental work around carers’ issues, for example getting involved in the development/updating of the local Carers’ Strategy.

**Key Messages for Carers Centres**

Most Carers Centres have established links with their local hospital trust/s, including representation on boards and groups. Many also provide services which support carers around the time of discharge. Perhaps the key question for centres is, with limited time and resources, what is likely to have the most impact? This study suggests that having clarity about the aims and intended results of the involvement of carers in the hospital discharge process, and being able to express and explain this in relation to national and local health priorities, is the first step. In addition:

- Establishing a cooperative and respected relationship with PCT and hospital staff at all levels of these organisations’ hierarchy, in particular at executive and at ward level, is central to the success of work with PCTs and hospital trusts. The importance of this relationship-building and the time it takes should not be underestimated and needs to be built into project aims and outcomes.
- Centres can use their relationship with their PCT and their involvement with a carers’ strategy or task groups to make the case for the PCT to include carers’ standards in their contracts with hospital trusts.
- Carers Centres should use existing partnership forums and structures to work with hospital trusts to encourage and support them in raising staff awareness of carers,
and changing systems and procedures to ensure carers are more likely to be identified, supported and referred.

- Pro-actively seeking and identifying a ‘Carers’ Champion’ at hospital trust executive or board level will help in mainstreaming carer awareness, identification and support into hospital trust discharge policies and procedures: for example, the recording of carers on electronic patient recognition systems and induction training for staff which includes carer awareness and information about who to refer carers on to for support.

- In relation to hospital-based projects:
  - Contact with a dedicated carer’s worker, who can provide or ensure that the carer gets access to practical and emotional support around the time of discharge, does make a difference to carers but a cadre of carers’ workers, who work both inside and outside the hospital, may be a more effective approach than that of a lone hospital discharge worker.
  - It is essential to start negotiations early with the hospital trust concerning working protocols and the practicalities of where workers will be based so that arrangements are in place as soon as the post commences.
  - It is important for carers’ workers to have a base where they have access to telephone and IT facilities and also where they can see carers away from the busy ward environment.
  - Carers’ workers need to have direct links with hospital discharge teams and be able to attend discharge forums.
  - Hospital staff need an easy way to refer or direct carers to the carers’ workers – if they have to complete a referral form or get the carer’s consent to pass their name onto the Carers Centre, the number of referrals will almost certainly be limited. ‘Surgery sessions’ in the hospital or information stands that are open at visiting time may be more effective.
  - The provision of accessible and timely information, together with systems for signposting carers to sources of help and advice, can clearly make the discharge process easier, especially for new carers. However, this needs to be clearly displayed in wards and departments and updated systematically.
Chapter 1

Introduction

In 2006 The Princess Royal Trust for Carers decided to undertake a piece of research and development work (funded by a grant from GlaxoSmithKline) focusing on support for carers in the process of hospital discharge. Specifically it aimed to examine what effect support for carers at the time of hospital discharge has on:

- avoiding delayed discharges
- reducing readmission rates for those being cared for
- improving the rehabilitation/recovery of the cared-for person
- improving the carer’s experience of the process of discharge
- enabling the carer to continue caring.

The research had two stages:

Stage One: Literature Review and Mapping Exercise

There were two main parts to this first stage of the study - a scoping review of the UK literature relating to carers and hospital discharge to provide an overview of the research evidence and; a mapping exercise designed to examine the work currently being done by the Carers Centres across England to support carers at the time of hospital discharge. A full report from Stage One was published in June 2007 and the key findings from this stage of the work are briefly summarised below in Section 1.3.

Stage Two: ‘Pilot’ Projects

In Stage Two, The Princess Royal Trust for Carers funded and supported two ‘pilot’ projects, one in Swindon and one in Barnet, which were designed to build on or test out ideas identified in Stage One.

Swindon – the Carers’ Hospital Liaison Worker started in post on 1 April 2008. The post is managed by Swindon Carers Centre but is located within Swindon’s acute general hospital, the Great Western. The overall aims of the Swindon project were to ensure carer involvement in discharge planning and to embed carer support into the day to day practice of the Great Western Hospital. It was intended that these aims will be accomplished through:

- the development of a set of carer standards to enable carers to know the level of service they can expect from hospital staff
- emphasising the early identification of carers by hospital staff and increasing the number of carers recorded in the ‘carer field’ in the Crescendo nursing information system

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2 Although the workers employed by the two projects have different titles (and roles), for ease they will, at times, be referred to simply as carers’ workers in this report.
work with staff to ensure that they involve carers as partners in care, ascertain carer support needs and inform the carer about any longer term support needs of the care recipient

- identification of ‘Carer Leads’ for each ward/area who will act as a resource for colleagues and update carer information within the hospital

- work with the Integrated Team in the hospital to identify re-admissions/admissions where carer breakdown has been identified as a potential cause

- the award of a Carers’ Charter to the hospital for its work on implementing the carer standards.

Barnet - the Carers’ Hospital Discharge Coordinator\(^3\) started in post on 4 March 2008. The post is managed by Barnet Carers Centre and there is also a Carers’ Hospital Discharge Steering Group in place to oversee the project and monitor its effectiveness. The aim of the project was to help reduce hospital admission rates amongst patients with Chronic Obstructive Pulmonary Disease (COPD), Ischaemic Heart Disease (IHD) and cancer by:

- ensuring carers are recognised by themselves and hospital staff as an integral member of the caring network

- improving the carer’s experience of the hospital discharge process through key support on an ‘intensive’ basis during the first 48 hours after discharge, and/or ongoing ‘regular’ support

- increasing the carer’s capacity to care if that is what they wish to do

- connecting carers with all relevant agencies and with other carers in similar situations

- motivating carers to care for their own needs.

The projects were evaluated over a two-year period, and an interim report from the evaluation was published in June 2009. This report is the final report from the evaluation.

1.1 Focus and Structure of the Report

This report sets out the findings from the two pilot projects. Chapter 1 briefly describes the methods used in the evaluation of the pilot projects and then summarises the key findings from Stage 1 of the project. Chapter 2 describes the policy context and also the results of the second national survey of The Princess Royal Trust for Carers Centres. Chapters 3 and 4 bring together the findings from the evaluation of both projects and these are grouped under two areas – ‘Changing Systems’ and ‘Changing Attitudes and Awareness’. Finally in Chapter 5 we draw a number of overall conclusions from the project as a whole.

\(^3\) Although the workers employed by the two projects have different titles (and roles), for ease they will, at times, be referred to simply as carers’ workers in this report.
1.2 Methods

Swindon – data were collected from the Swindon project through questionnaires given to carers and hospital staff, focus group interviews and telephone interviews. Questionnaires were either sent to carers in the post or given to them by support workers from Swindon Carers Centre. All carers who were invited to fill in the questionnaire cared for someone who had been discharged from the Great Western Hospital between July 2008 and December 2009. The views of staff were collected through questionnaires distributed throughout the hospital in November 2009, and also through two group interviews which were held in October 2009. Additional data were obtained through telephone discussions with the Carers’ Hospital Liaison Worker and two senior managers at GWH.

Barnet – data were collected from the Barnet project through questionnaires given to all carers who had had contact with the CHDC and also through questionnaires given to staff in the three target specialties. Additional data were collected through telephone discussions with the Carers’ Hospital Discharge Coordinator and a senior manager at Barnet and Chase Farm Hospital.

Note about the surveys of carers – two small surveys of carers were conducted by the pilot projects; the first in early 2009 and the second approximately 10 months later. The findings from these surveys were disappointing as they showed no real improvement in the experience of carers. However, the results need to be treated with a great deal of caution. This is because the number of responses to both the baseline and the follow-up surveys was very low (especially in Swindon) but also because those carers who had had a bad experience may have been more likely to respond, so skewing the result. It is also important to recognise that it takes time to change systems and practices and so it may be sometime before the work the projects have done is reflected in carers’ experiences. Because of these issues, we have not given detailed results on the findings from the carers’ surveys in this report but, where appropriate, data have been incorporated into other sections of this document.

1.3 Key Findings from Stage 1 of the Project

The section below is a summary of the report produced at the end of the first stage of the project in June 2007 (see footnote 1 above); for an up to date discussion of the policy context please see section 2.1 below.

Successive government policies have highlighted the need to inform and involve carers fully in the hospital discharge process, but research reports published over the last ten years suggest that many carers feel insufficiently involved and unsupported in the process of hospital discharge. Furthermore, while hospital discharge policies often refer to the need to involve carers, evidence suggests that in many hospitals, with high occupancy rates and the pressure to release beds, staff cannot be relied upon to identify and support carers. In some areas, schemes have been established specifically to support carers through the transition of the cared-for person from hospital to home, but few of these initiatives have been evaluated or written up in a way that can help other hospital trusts and carers’ organisations improve support for carers in their own area.

The literature review found that overall, there appears to be a dearth of primary research which evaluates specific interventions to improve the process of hospital discharge for carers. Of the 18 primary research studies considered relevant, only five actually involved an intervention and none of these were aimed directly at the discharge
process as it related to carers. The majority of the remaining research documents examined patients’ and/or carers’ views on the process of discharge and were mainly qualitative in nature. Of the 10 policy documents identified the majority were government publications, and all emphasise the importance of involving carers in the discharge process.

In terms of the provision of services, many of the documents reviewed either described services available to support carers through the process of hospital discharge of the cared-for person or discussed the effect on the carer of certain services pertaining to hospital discharge. A number of documents also discussed the issues involved in providing services to support carers at this time. The types of services described included: provision of discharge/information packs for patients and their carers, specialist carers’ workers, ward-based discharge co-ordinators, training for staff and/or carers, schemes to support carers at home immediately following discharge, hospital discharge agreements/policies, ‘hospital-at-home/early discharge schemes and pre-discharge home visits.

The evidence relating to the effectiveness of services was examined under the themes set out for the overall study (see page 6). The areas for consideration emerging from this literature can be summarised as follows:

- the need for communication with and involvement of carers at all stages of the discharge process
- the importance of acknowledging carers’ needs and their right to an assessment
- the recognition that the carer’s views and wishes are not always the same as those of the cared-for person and the need to consider how to balance the two
- the potential value of the carers’ specialist/key worker role
- the importance of ensuring that carers are fully aware of the options available to them
- the benefits of ongoing support and follow-up for the carer, both pre- and post-discharge
- consideration of the timing of discharge and whether the carer is fully involved in the decision-making process concerning when the cared-for person leaves hospital
- a recognition that poor discharge planning can lead to stress and anxiety in the patient and carer, a possible reduction in the carer’s ability to care and potential unplanned re-admissions
- the advantages to both the patient and the carer of the involvement of, and participation in, the multi-disciplinary team
- the potential value of training for carers
- the necessity of encouraging communication across health and social care
- the need for increased awareness of the carer role amongst hospital staff.

The messages which emerge from the research literature about what principles and practices might lead to effective support for carers at the time of discharge, and what policy makers expect from organisations working with carers, are relatively clear and consistent. In particular the literature suggests the need for:

- high levels of carer awareness amongst hospital staff – this might be achieved in many different ways (e.g. staff induction and training; designating a ‘carers’ lead’
for each ward; joint work between carers’ workers and ward staff; the creation of a carers’ charter setting out the hospital’s responsibilities to carers) but it has to be there or all other initiatives to support carers are likely to be less effective because carers will not be recognised, recorded and referred.

- **policies and procedures which recognise carers** – while carer awareness is the foundation of good support, it needs to be reinforced by policies and procedures, which emphasise the importance of involving carers in the discharge process at an early stage, acknowledge their needs and rights, and then enable staff to record carers’ details and wishes.

- **easy access to information and signposting of carers** – the provision of accessible and timely information together with systems for signposting carers to sources of help and advice can clearly make the discharge process easier, especially for new carers but they are likely to be more successful if they are accompanied by high levels of carer awareness and the right policies/procedures.

- **direct support and advice to carers** – support and advice can be provided in many different ways, but the literature indicates that two ‘interventions’ may be particularly helpful – i) access to a specialist carers’ worker who can provide, or ensure that carers get access to, practical and emotional support both pre- and post-discharge and ii) training for carers prior to the cared-for person being discharged.

In the mapping exercise 51 of the then 87 Carers Centres in England returned a completed questionnaire, giving a response rate of almost 60%. Nineteen of the centres responding reported that they provided a service designed to support carers when the person they cared for was being discharged from hospital. A further 22 centres noted that they had plans to develop targeted services but these plans were at very varied stages of development/ progress. Many of the other centres noted that although they did not have dedicated services, their core services did provide support to carers around hospital discharge.

Centres were asked to provide a brief description of any services/projects they run or contribute to which are designed to support carers when the person they care for is being discharged from hospital. Five main ‘aims’ emerged, with services often having several aims:

- Identification and signposting of carers
- Direct support and advice to the carer
- Training for carers
- Provision of information
- Raising awareness and changing systems.

Most services were available to any carer of any patient using acute care in the centre’s area. The majority were being run by the Carers Centres themselves (15). Two were run by the Carers Centre jointly with the hospital trust, one was run by the county council and the PCT, and another by the PCT. Several centres noted that the funding for the service had come from more than one source.

The centres were asked what, in their view, had been the impact of their service and their responses suggest that the main observed impact has been on improving the carer’s experience and enabling the carer to continue caring, rather than on avoiding delayed discharges and reducing admission rates which are much harder for centres to assess. Of the 19 services described, only two had been evaluated externally, six had
been evaluated internally and ten reported not having carried out any form of evaluation to date (one centre noted that their service had been evaluated internally and externally).

While the mapping exercise showed that several centres have tried to put in place services and/or initiatives designed to make these principles and practices a reality, in many areas there is still a gap between what policy and research says should happen and what actually happens to carers as the person they care for passes through the hospital system. Even where services and initiatives to support carers through the discharge process exist, there is only limited evidence from evaluation to demonstrate their impact on the carer’s experience, and even less evidence which shows that such support can ensure discharge takes place at the appropriate time, reduce re-admission rates, and improve the rehabilitation or recovery of the person being cared for person.
Chapter 2
National Context

2.1 Policy Context

Local Authorities and the NHS share responsibility for patients at point of discharge. Statutory guidance issued following the 2003 Community Care (Delayed Discharges etc.) Act advises that carers should be involved in discharge planning and that they can ask for an assessment (under the Carers and Disabled Children Act) of any services they need to support the discharge of the person they care for. Should a hospital trust identify that someone is a carer, it should inform them of their right to a carer’s assessment and either advise them to contact their Local Authority or (with their permission) refer them for this purpose.

2.1.1 The Carers’ Strategy

In 2008 the Carers’ Strategy ‘Carers at the heart of 21st-century families and communities’ was launched. The Strategy envisions five outcomes to be achieved for carers by 2018:

- Carers will be respected as expert care partners
- Carers will be able to have a life of their own
- Carers will not be forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well
- Children and young people will be protected from inappropriate caring roles.

Effective support for carers during the discharge process has a role to play in achieving all five of these outcomes for carers.

Carers have often been caring for many years, building extensive knowledge of the patient’s condition and health. Involving carers and providing them with information can improve the care given to the patient and the recovery of the patient post discharge. If carers are not consulted and involved in discharge plans, they can find that caring responsibilities which are forced upon them may negatively affect their own life choices such as ability to work. A recent report cited evidence that two-thirds of carers had not

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been asked whether they could cope after the discharge of their care recipient from hospital.\(^7\)

Giving up work, as one in five carers do,\(^8\) increases the risk of financial hardship which can exacerbate the poor health that carers disproportionately suffer. Being thrust into a caring role unprepared without training in first aid or moving and handling, and without being referred to support services, can leave the carer overwhelmed causing their own health to deteriorate.\(^9\) \(^10\) Providing high levels of care results in a 23% higher incidence of stroke\(^11\) and 20% of carers suffer a back injury caused by caring.\(^12\)

The Association of Directors of Adult Social Services (ADASS) believes that the need for young carers to be kept informed may not be recognised. Greater recognition, involvement and sharing of information can help assuage the concerns of young carers without increasing the burden upon them.\(^13\) Young carers may need extra support to ensure their caring roles are not becoming too heavy.\(^14\)

The Carers’ Strategy advises that carers should be involved in all care planning from diagnosis to discharge and beyond. This means that carers should have information relevant to the care and needs of the people they support.\(^15\)

### 2.1.2 Carers in other strategies

The National Stroke Strategy\(^16\) promotes carer support throughout the patient journey. The Strategy focuses on early supported discharge and this is often unachievable without carer support. The Strategy includes a number of quality markers (QMs) for NHS bodies to work towards, including:

- patients and carers have access to practical advice, emotional support, advocacy and information throughout the care pathway and lifelong (QM3)
- patients and carers are involved in developing and monitoring services (QM4)
- a range of services needs to be locally available to support the individual long-term needs of people who have had a stroke and their carers (QM13)
- patients and carers are offered a review from primary care services of their health and social care status within 6 weeks of discharge (QM14).

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\(^9\) ADASS (2010) – as above  
\(^12\) The Princess Royal Trust for Carers (2004) – as above.  
\(^13\) ADASS (2010) – as above.  
\(^15\) HM Government (2008) – as above  
The Princess Royal Trust for Carers ‘Out of Hospital’ Project – Learning from the Pilot Projects
Final Report – May 2010

The End of Life Care Strategy\(^{17}\), The Dementia Strategy\(^{18}\) and Valuing People Now\(^{19}\) (a strategy for people with learning disabilities) all advise that carers should be treated as ‘co-workers’ with the health and social care team. This means that they should be offered information about the person’s condition, closely involved in decision-making from diagnosis onwards and offered support in their caring role.

2.1.3 Carers and the NHS

One of the seven principles of the NHS Constitution\(^{20}\) is that carers are involved in decisions about care and planning. In addition, one of the six values of the NHS involves staff working with carers to provide better care\(^{21}\). Other Government reports highlight the need to involve and support carers throughout the discharge process. Putting People First,\(^{22}\) which sets out the vision to transform social care, advises that local authorities and NHS bodies should produce “an integrated approach...to achieve specific outcomes on...hospital discharge arrangements” (p.3).

NHS 2010-2015: From Good to Great\(^{23}\) emphasised that carers had previously not been sufficiently recognised as expert care partners and that there was a need for this to change. As a result of this, the NHS Operating Framework 2010/11\(^{24}\) advises that carers should be recognised as expert partners in care. NHS 2010-2015 also recommended that better support for carers, including carers being involved in the discharge process, could reduce emergency admissions or readmissions.

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\(^{21}\) Department of Health (2010) – as above


The NHS Operational Plans for 2008/09 – 2010/11\textsuperscript{25} set the performance indicators for PCTs in England. These are separated into three tiers with Tiers 1 and 2 being national priorities. The indicator related to carers is in Tier 3, meaning that PCTs can choose whether to be measured against this indicator or not. The performance indicator is the proportion of carers receiving a ‘carer’s break’ or a specific carers’ service as a percentage of clients receiving community-based services.

2.1.4 Patient Reported Outcome Measures (PROMs)\textsuperscript{26}

PROMs are measures of a patient’s health status or health-related quality of life. From April 2009, all licensed providers of hip replacements, knee replacements, groin hernia surgery and varicose vein surgery will be expected to invite patients undergoing one of these procedures to complete a pre-operative and post-operative PROMs questionnaire. Both the pre-operative and post-operative PROMs questionnaires include a question about the patient’s living arrangements. The post-operative PROMs questionnaire also includes questions about readmissions to hospital and rehabilitation. The collection of such information could be cross-tabulated with records of where the patient had a carer to quantify the carer’s impact on successful outcomes. Commissioners may find that supporting carers has an impact on rehabilitation and readmission rates.

2.1.5 Quality, Innovation, Prevention, Productivity (QIPP)\textsuperscript{27}

In preparation for reduced spending growth, the NHS is currently undertaking the ‘QIPP challenge’ to increase quality while improving efficiency. The Department of Health wants to support innovation in clinical practice and develop pathways which improve effectiveness and enhance the patient experience as well as providing value for money. They believe that by focussing on Quality, Innovation, Prevention and Productivity, they can improve efficiency and save NHS resources while delivering high quality care.

The DH believes that, in line with best practice, far more care should be delivered in a patient’s home or community.\textsuperscript{28} This requires improved co-ordination between health and social care, and also primary and secondary care as set out in the NHS Operating Framework 2010/11. It is believed that some emergency admissions could be prevented with better community services and there should be a co-ordinated effort to improve out of hospital care. Moving care from hospitals to home necessitates working with carers to ensure that they have the skills, knowledge and confidence to provide that care. They need to be part of the team that plan and deliver care. This point was emphasised by David Nicholson CBE, Chief Executive of the NHS, in a letter to all


\textsuperscript{28}Department of Health (2010) – as above
Chairs and Chief Executives in the NHS when advising that co-production of services must be a guiding principle\textsuperscript{29}.

Commissioning for Carers\textsuperscript{30} shows how the World Class Commissioning process can be carried out by commissioners of carers’ services and provides a blueprint for buying services to help carers. Its starting point is setting out a model of comprehensive carer services that are needed in every local area to achieve the Carers’ Strategy’s vision for carers. Health and social care commissioners need to consider what services currently exist and where local need for other services may be greatest. These considerations should be part of the area’s Joint Strategic Needs Assessment which allows health, social care, users/carers and providers to plan commissioning and delivery of services. This is the type of collaborative work encouraged by the NHS Operating Framework and Next Stage Review to achieve the quality and efficiency gains needed in the NHS.

### 2.2 National Survey of Carers Centres

#### Summary of Results

- The majority of Carers Centres had established links with their local hospital trust/s and almost a fifth had representation on boards or groups.
- More than half the Carers Centres reported that local discharge policies referred to carers but only a small number were aware of their local hospital trust having a carers’ charter or a carers’ champion at executive level.
- Only three hospital trusts were known to have carers’ leads on their wards and departments and less than half provided staff with information about identifying and supporting carers.
- All except one Carers Centre reported that information for carers was available on the wards at their local hospital but several noted that it was not displayed or updated systematically.
- Half the Carers Centres had services or projects aimed at supporting carers around the time of discharge.

The second national survey of Carers Centres focused on their links with local hospital trust/s and drew on their knowledge of the hospital trusts’ policies and systems in relation to carers. It also asked about what information was available, both for staff working or liaising with carers and for carers themselves. Finally, it briefly asked Carers Centres about the services they provide to support carers at the time of discharge. Twenty nine of the 103 Carers Centres in England returned a completed questionnaire, giving a response rate of 33%. Below is a synopsis of results from the survey; more detailed results can be seen in Appendix 1.

\textsuperscript{29}\url{http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_104239}

2.2.1 **Links with local hospital trusts**

Ninety percent \((n=26)\) of Carers Centres had established links with their local hospital trust. These links ranged from informal/infrequent contacts to much more formal integration, information sharing and representation. One Carers Centre had established a discharge project within their local hospital trust (with Department of Health funding) which was being piloted at the time of the survey. Two of the centres reported that they had information stands at their local hospital trust and four centres had their own employed Carer Support Workers who worked within the local hospital trusts to provide information and support to carers. Five centres \((17\%)\) reported having representation on various groups and boards associated with carers’ services in their local hospital trust and two centres were involved in setting up new project work with their local hospital trusts.

Twelve centres indicated that they were struggling to find the capacity and/or resources to do justice to work they would like to do with their local hospital trusts. This was particularly a problem for centres which were located in an area served by more than one acute hospital because Carers Centre staff then had to build relationships with several hospitals.

2.2.2 **Hospital policies and systems**

Many of the Carers Centres were not aware of the policies and systems which were in place in their local acute trusts. The process which centres appeared to know least about was whether information about carers was recorded on the local hospital trust’s electronic patient administration system. Nearly two thirds of centres \((19)\) did not know whether there was a system in place and only one of the centres knew that their local hospital trust did have a system for recording carers. Only five Carers Centres were aware of a Carers’ Charter or Carers’ Standards in place in their local hospital trust and only six hospital trusts were known to have a Carers’ Lead or Carers’ Champion at Board and/or Executive level. Nearly two thirds of centres \((19)\) were aware of discharge policies and procedures in their local hospital trust, and whether carers were referred to in these. Of these, sixteen were known to refer to carers within their discharge policies and procedures.

2.2.3 **Information and support to hospital staff**

Twelve Carers Centres said that their local hospital trust provided staff with information about carers, however this was provided by the Carers Centres themselves in four hospitals. Four centres also commented that despite their local hospital trust offering training this was often infrequent and \textit{ad hoc}, with one centre explaining that it is often difficult to release staff to undertake the training offered. Just three hospital trusts were known to have carers’ leads on some or all of their wards. Twenty four centres reported that there were carers’ workers working in their local hospital trust. Most were employed by the Carers Centres themselves although a small number were employed by the local authority. Several had NHS funding contributing toward the cost of the roles. The number of workers varied from one, to a maximum of eight workers being employed in one hospital trust.

2.2.4 **Information to carers**

Twenty-six Carers Centres reported that information was available to carers on the wards in their local hospital trust, although six respondents implied that the information is not displayed or updated systematically in all wards. Where centres offered details on who maintained this information, this was most commonly done by Carers Centre staff.
2.2.5 Carers’ support services and projects
Fifteen Carers Centres were involved in services or projects aimed at supporting carers around the time of discharge. Of these, 13 projects were being run by the Carers Centre themselves, with two centres being involved in projects run by other organisations (one with their local PCT and other voluntary organisations, and another with their local council). Respondents’ definitions of ‘service/project’ appeared to vary widely from ad hoc work in the hospital or production of an information leaflet to large scale multi-disciplinary projects designed to change admission or discharge patterns.

Twelve centres described well defined aims for their service or project, while one centre reported being in the early stages of development with their local council and had not yet agreed aims. One of the centres referred to a detailed publication relating to their project which had been produced in liaison with another carers’ organisation. All service/project aims fell within one or a number of the following areas:

- Supporting carers through the discharge process
- Supporting carers in order to prevent unnecessary admission and re-admission
- Establishing support within the hospital itself, particularly in relation to discharge
- Training and increasing knowledge and awareness of carers’ needs amongst hospital staff.

Nine centres cited barriers which they had experienced in relation to their service/project. The most common barrier, cited by five centres, was in establishing a respected and cooperative relationship with hospital staff. Existing hospital systems were also a barrier for three centres which had experienced difficulty with clinical database systems and also in trying to integrate their service with existing systems and processes. Other barriers cited were changes to budgets and national guidelines, communication about the project within the hospital and getting information onto the hospital wards. A few centres said that they had been able to overcome some of these barriers but not many details were provided relating to how this had been achieved. There appeared to be a general suggestion that simply by maintaining a presence and keeping links, the situation had improved over time.

When asked about what had worked well, ten centres responded with details of benefits arising from their service/project. One centre which had undertaken a wide-scale training and awareness project within their local hospital trust reported that they had seen benefits. However, they recognised the need to reach many more healthcare workers in order to lead to any significant benefits.

Many projects were ongoing but benefits reported to date included the raised profile of carers within the hospital setting, improved partnership working with the hospital trust, success in influencing hospital processes, increased referrals to Carers Centres and improved support for carers.
Chapter 3
Changing Systems

Summary

- The projects showed that it is possible to change key systems so that the identification and referral of carers is improved but it is difficult and time consuming, especially where a change in IT systems is required.
- Having a carers’ champion at executive level or at least having high level support for carers’ issues is vital. If this can be coupled with a hospital trust-wide group that has a remit to improve services for carers greater progress is likely to be made.
- Carers’ workers need to have direct links with hospital discharge teams and be able to attend discharge forums.
- If part of the carers’ worker’s role is to provide direct support to carers, having an easy way for staff to direct or refer carers to the service is essential.
- The carers’ worker also need a place where they can see carers away from the busy ward environment.

This chapter examines ways in which the carers’ workers’ roles have influenced the systems in place in the two pilot sites, in order to improve the identification, recording and referral of carers. It also examines what has facilitated the carers’ workers in the implementation of new systems and what difficulties they have encountered. The data are mainly taken from the stakeholder interviews in both Barnet and Swindon and interviews with the two carers’ workers.

3.1 Prior and Existing Systems

Before the carers’ workers commenced in post there were no similar roles in place in either Swindon or Barnet. At GWH in Swindon, however, there had been a Carers’ Development Worker until 2004. The Head of Operations at Barnet and Chase Farm Hospital recognised that carers had not been given as much attention as they should have been prior to the CHDC coming into post.

3.2 Partnerships

In Swindon, there is a Carers’ Partnership Board which is chaired by the PCT with representation from Great Western Hospitals NHS Foundation Trust, Swindon Carers Centre, Swindon Borough Council Social Services and other NHS trusts, such as the mental health trust. Their role is to oversee the local Carers’ Strategy and the Carers’ Grant. The contract between NHS Swindon (PCT) and GWH includes quality markers for carer standards. Regular reporting is required by GWH to monitor the contract. The Trust Lead for Carers at GWH felt that the hospital’s links with Swindon Carers Centre had been “a real bonus.”
In Barnet, there was a project Steering Group initiated for the CHDC post but unfortunately they experienced some difficulties; attendance was sporadic, not highly prioritised and was also affected by a number of staff changing posts. Changing the meeting venue to the hospital site improved the situation somewhat, however. It had been thought that there would be a large number of referrals for the group to oversee as a result of the project but this did not happen.

3.3 New Initiatives

3.3.1 The role of the carers’ workers in setting up and implementing new systems

In both Swindon and Barnet the carers’ workers have had an impact on the development of new systems and policies. In Barnet, a change in the discharge policy to make greater reference to carers was being considered and this was as a result of the ‘Out of Hospital’ project. A change in the admission paperwork was also being considered. In addition, it was hoped that carers identified through the carers’ field on the hospital discharge system (JONAH) would, with their permission, be referred to the CHDC but this has been slow to take off. Unfortunately, the field was not really being filled in consistently as some departments, such as A&E, were ambivalent about asking patients whether they had a carer/were a carer on admission.

A number of new systems and policies, such as the Carer Screens on the Crescendo electronic nursing system, have been set up in Swindon as a result of the CHLW; these are discussed in more detail below. The DDN at GWH in Swindon indicated that the CHLW “has been instrumental in making sure processes and systems are in place”.

3.3.2 New initiatives in Swindon

As a result of the CHLW, several new initiatives have been implemented at GWH in Swindon. These are: the Carers’ Task Group, the Carers’ Action Plan, Carer Screens on the Crescendo electronic nursing system, the ratification of the Carers’ Policy, carer awareness training for staff, Carer’s Leads in most clinical areas and information for carers on all wards and on the hospital trust’s website. The hospital has also hosted two Carers’ Day events. The Trust Lead for Carers believed that as a result of the CHLW role “things have moved forward in terms of training, awareness and systems”.

Carers’ Task Group

This is chaired by the Trust Lead for Carers. There is representation on it from senior nurses from each directorate, as well as members from the IT department, the training department, the social work team, the human resources team, a patient/carer representative and a non-executive director. The CHLW is also in the group. It meets once every two months and its function is to implement the Carers’ Action Plan and to improve services for carers within the hospital trust. From April 2010 the group will continue to meet as the Carers Strategy Committee to oversee the ongoing work in relation to carers issues at GWH.

Carer Screens on the Crescendo Nursing System

The CHLW spent a significant amount of time over the course of the project negotiating with the IT department at GWH in order to establish ‘carer screens’ on the electronic nursing system Crescendo. In April 2009, the screens were set up in the ‘notes’ section of the system and as such, according to staff interviewed in the focus groups and also the Trust Lead for Carers, were “in the wrong place”. It was felt that in order for staff to consistently fill them in, the screens needed to be in the ‘demographics’ section because it was necessary to proactively search for them in ‘notes’. Staff felt that it was difficult
enough to find the time to fill in the mandatory screens on Crescendo without having to spend time searching for the correct place to input carer information.

“Getting staff to fill in the Crescendo is a major problem, mostly because we are still short-staffed.” (Swindon focus group)

“It just gets lost, with all the other stuff that needs to be done. But it’s not to say we’re not talking to the family or talking about these issues and sorting them out. It’s just not getting put on Crescendo.”

(Swindon focus group)

Some staff thought that it would be useful to have an alert about carers on Medway (the electronic medical history system) as well as on Crescendo. At present, there is space for recording next of kin on Medway but nowhere for carer information.

Very recently, the CHLW has managed to negotiate an update to Crescendo with the IT team which involves a new assessment. If the answer to either of the questions ‘Are you a carer?’ or ‘Do you have a carer?’ is ‘yes’, then staff will be advised to complete the carer note on Crescendo. Once the assessment is available on Crescendo it will be included on the report that Ward Managers currently receive about the other mandatory assessments, so that missing assessments can be completed.

3.4 What has facilitated the setting up of new Systems

In Swindon, it was felt that the CHLW’s work in ‘marketing’ her role and “selling the message” had had an impact in relation to facilitating the setting up of new systems and practices. Because of this, ward managers and carers’ leads had seen the advantage of identifying carers early and involving them in decisions about the care and discharge of the person they cared for. High-level support from people such as the Director of Nursing, the Deputy Director of Nursing and the Trust Lead for Carers had also had an influence on the ease with which new systems had been introduced and accepted.

In Barnet, the CHDC’s regular attendance at the weekly hospital Discharge Forum in the early stages of the project had helped to raise the role’s profile among hospital staff and hence facilitate the introduction of new initiatives and practices.

3.5 Difficulties in setting up new Systems

Practical issues caused difficulties in both Swindon and Barnet. Hot desking and not having a dedicated telephone line initially meant that it was hard for the CHLW in Swindon to be available consistently, although once she was allocated a desk and phone this situation was improved. In Barnet, poor availability of equipment, such as computers and telephones, caused the CHDC a number of problems and the lack of storage space for files and paperwork was also an issue. Some potentially useful resources were prohibitively expensive, such as a hospital bleep (£2,000) and encryption of the CHDC’s laptop (several hundred pounds). Being awarded honorary contracts within the hospitals was essential for obtaining ID cards, gaining access to the computer systems etc for both the carers’ workers but they did not receive these as early as they would have liked. Ideally, these would be set up by the time the post-holders took up their roles. It was felt by the CHDC that the hospital system was very bureaucratic and permissions had to be obtained from a number of sources to complete simple tasks such as putting up posters.
As mentioned above, problems were encountered in relation to establishing the ‘carer screens’ on the Crescendo nursing system in Swindon. The CHLW felt that some organisational problems were outside her control and that the only way to effect any changes was to be persistent. Spending time actually working with staff was also a problem for the CHLW in Swindon. This was mainly to do with the busy nature of hospital life and the workload pressures on staff; they simply did not have enough time to attend training sessions.

The CHDC in Barnet encountered difficulties when, in order to improve identification, he tried to introduce a new question on the nursing admission assessment to find out if the patient had a carer. The hospital trust did not actively oppose the idea but no progress was made. More recently, there has been some hope that this new change might be made because the Learning Disabilities Tracker Nurse at Barnet hospital has been working towards introducing a similar question for carers of people with learning disabilities. This was in response to a forthcoming requirement by the Care Quality Commission (CQC) that all hospital trusts must identify the carers of people with learning disabilities who are admitted to hospital. The LD Tracker Nurse and the CHDC have been working together to encourage the hospital trust to implement the change on all admission paperwork and not just that for patients with learning disabilities.

The CHDC in Barnet and the CHLW in Swindon both tried to introduce a carer awareness ‘slot’ on to their hospital trust induction programmes but unfortunately these were both rejected as the induction programmes were said to be too full already. Subsequently in Swindon, however, one slide relating to carer awareness had been included in the general presentation at the start of the induction course. In Barnet, the hospital trust gave the CHDC the option of including a leaflet in the information pack given to new employees but they suggested that it should be ‘punchy’ as there was already a large amount of information for new staff to assimilate. The CHDC therefore produced a short flyer to be included in the pack.

Because of the CHLW’s increased success in introducing new practices and systems in Swindon as a result of getting the Director of Nursing ‘on board’, the CHDC in Barnet also tried to involve the Director of Nursing at Barnet and Chase Farm hospital with the carers’ work he was undertaking but owing to other commitments, it was difficult for the DN to dedicate much time to assisting the CHDC. The CHDC found the hospital to be a very ‘political’ environment where managers were often motivated by a range of agendas and targets which do not necessarily coincide with focusing on carers’ issues. The CHDC felt that trying to effect change at an operational level was an uphill struggle – “it’s a question of constant profile-raising”.

### 3.6 Successes

In Swindon, the Trust Lead for Carers and the DDN felt that the main successes of the CHLW role had been raising the awareness of staff concerning identification and recording of carers and also the staff training that the CHLW had introduced. It was also thought that signposting of carers had been improved. The DDN believed that there was ‘sign up’ from all members of staff in relation to recognition and involvement of carers. The CHLW felt that the greatest success had been in the introduction of new organisational initiatives such as the Carers’ Task Group, the Carers’ Policy, the Carers’ Action Plan and the Carers’ Leads on the wards.

“There’s been an organisational push to take things forward.”
In Barnet, the Head of Operations believed that any success was due to the efforts of the CHDC:

“[The CHDC] was great. He put 110% effort into making the project work.”

The CHDC thought that in the areas of the hospital where he was most involved he had become integrated and the staff knew him and were referring to him. The promotional activities that he had run (such as the Chocolate Promotion, where a box of chocolates was sent to the ward that had made the most referrals in a particular month) had been successful. They were well received by wards and helped to raise the profile of the project. Having a presence on the hospital intranet (for a while as a screensaver) had also helped to raise the profile of the project amongst staff. The Carers Centre stall in the hospital entrance was thought to have been a success, although carers were much happier just to take information rather than give their details.

3.7 Lessons for the Future

Various lessons have been learnt in relation to setting up new systems within the hospitals. In Swindon, it was felt that an attempt should be made to sort out any IT problems as early on as possible within projects of this kind and that communication about the role should also be a priority, especially in the early stages. In Barnet, the CHDC believed that a number of things could have been done differently which may have improved the implementation of new practices and increased the effectiveness of the role. These were:

- having set ‘surgery times’ when hospital staff could direct carers to the CHDC or even book them in
- having a set place where carers can go and see someone face to face, rather than trying to talk to them on a busy ward
- having a more ‘network’ approach to the work with carers e.g. setting up a generic ‘help-point’ with other organisations within the hospital
- being realistic about what the hospital trust is able/willing to do – often the CHDC was promised things that never actually happened.

3.8 Sustainability

In Swindon, it was felt that the systems that had been set up, such as the Carers’ Task Group and the Carers’ Leads, would ensure continuing awareness of carers and carers’ issues. The Task Group will ensure that they progress with the Carers’ Action Plan and achieve its aims. It is possible that the CHLW role could be continued as a multi-funded post i.e. jointly between Swindon Carers Centre, Swindon PCT and Swindon Borough Council with the acute trust providing the accommodation. The NHS in Swindon (including GWH, as well as community health services, mental health and GP services) is also to become a Demonstrator Site for a Department of Health project which aims to provide better services for carers so this may take up some of the work of the CHLW.

In Barnet, there was no clear vision as to how the work of the CHDC may continue. Attempts were made to find continuation funding but none was forthcoming. However, the Carers Centre still want to maintain a presence in Barnet Hospital. The stand in the
hospital entrance was manned partly by volunteers and it is planned that this happens full time after the CHDC role comes to an end. The hospital social work team have also agreed to take some responsibility for the stall. In addition, the Head of Operations at the hospital has agreed for a volunteer to attend the JONAH discharge meetings to keep carers’ issues current. The CHDC was concerned that if the Carers Centre “drops out of sight” it will take a long time for the profile to be built up again.

Carer support is Tier 3 priority for the NHS (as outlined in the 2010-11 NHS Operating Framework [Dec 09]) which means that carer support projects are reliant on hospital trusts to make carers’ issues a local priority. In reality, therefore, carer projects like the ‘Out of Hospital’ project may have to rely on hospital staff choosing to identify, record and refer carers rather than there being minimum requirements which can then be regulated by the Care Quality Commission.
Chapter 4
Changing Attitudes and Awareness

Summary
- Many hospital staff are not clear about the definition of the word ‘carer’, and many family members who provide care and support do not identify themselves as ‘carers’. 
- Having questions about carers built into core systems such as admission and assessment processes, nursing information systems and discharge planning systems is absolutely vital for identifying carers.
- Carers also need to be encouraged to identify themselves and good communications between ward staff and families can make a big difference to them doing so.
- Heavy workloads and pressure to release beds have a major impact on the capacity of staff to identify, record and refer carers.
- Most staff see the benefit of involving carers in the discharge process and agree that they should be regularly and systematically involved.

This chapter examines staff attitudes towards, and awareness of, carers and carers’ issues within the two pilot hospital trusts. The data are drawn from the staff surveys in both Barnet and Swindon, the staff focus groups in Swindon, interviews with stakeholders in Barnet and Swindon, interviews with the carers’ workers at both sites and the carers’ survey. Twenty-four completed staff questionnaires were received from both Barnet and Swindon (48 in total) with half of the respondents from both sites being nurses. A total of 23 members of staff took part in the two focus group interviews in Swindon; 13 in one and 10 in the other.

4.1 Definition of, and Problems with, the Word ‘Carer’

Many members of staff (in both of the pilot sites) did not appear to be clear about the definition of the word ‘carer’. Although the majority said that a carer was someone who offered support, help or assistance to another person, only a few explicitly said that carers were people who looked after family/friends in an unpaid capacity. Problems related to the definition of the word ‘carer’ were thought to hinder the easy identification and recording of carers within the hospital setting. There was still sometimes confusion between carers and care workers amongst staff (as had been the case in the first staff survey). The problems were thought to be compounded when many carers themselves either do not know that they are ‘carers’ or do not want to be identified as such. A number of staff described how some carers see themselves as the patient’s spouse or child or friend rather than their ‘carer’ and view what they do for that person as a natural part of their relationship with them.
4.2 Awareness of Carers and Carers’ Issues

In Swindon, the staff who attended the focus groups discussed the level of awareness of carers and carers’ issues among the staff in the hospital. It was thought that awareness still varied from ward to ward but that the CHLW had done a lot to raise the profile of carers, particularly through promoting events such as Carers’ Rights Day and Carers’ Week within the hospital:

“They have greatly raised awareness.” (Swindon focus group)

More information about carers is now available for staff, for example, carer awareness is now part of the hospital trust induction programme and there is more information on the hospital trust’s intranet. Both the Trust Lead for Carers and the Deputy Director of Nursing in Swindon felt that the presence of the CHLW had had a significant impact on staff awareness of carers and carers’ issues and that this increased awareness had positive corollaries for carers and also for patients.

One area in which awareness appears to have been raised is in relation to the potential discrepancy between a patient’s views and those of their carer. Staff need to be aware that patients and their carers do not always agree on the appropriate course of action or on the way things work at home. It is also important for staff to realise that some care recipients take their carers for granted. Carers need to be supported and listened to; they also need to know that they have a choice. If staff are aware of these issues then that support can be given and/or carers can be signposted to appropriate services.

Although she believed that awareness was improving, the CHLW in Swindon felt that some members of staff still had entrenched attitudes with regard to carers and did not feel that it was their responsibility to support them. They believe that their focus should be solely on the patient. The CHLW indicated that she is trying to challenge these attitudes whenever possible.

One carer’s comment seemed to indicate that there is still some way to go in relation to hospital staff’s awareness of carers:

“When I asked for information I was ignored.”

4.3 Awareness of the Carers’ Workers

In Swindon, just under half of the staff surveyed were aware of the CHLW but this was a slight improvement on those who were aware at the time of the interim report (42%). The Deputy Director of Nursing in Swindon believed that presence of the CHLW had made staff realise that carers have to be part of patient care and discharge planning. The CHLW’s enthusiasm had enthused staff. She described the CHLW as “invaluable” and believed that they would be “lost without her”.

“She’s been significant in the success of this work.”

In Barnet nearly 90% of those surveyed were aware of the CHDC. 31 There were many comments made about the CHDC role and its usefulness.

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31 The much greater proportion of staff who were aware in Barnet, compared to those who were aware in Swindon, may partly be a reflection of the fact that only staff in the three target specialities were surveyed in Barnet, whereas the whole hospital was surveyed in Swindon.
“Very relevant and beneficial role.”
“Really helpful and useful, very supportive to carers.”
“It is a very valuable role within the hospital. In fact, there should be more of them.”
“The role of the Carers’ Hospital Discharge Coordinator is very important to me as it helps facilitate discharge in an effective and safest way.”

4.3.1 Attendance at carers’ workers’ training sessions
In Swindon, only 17% of staff who returned the survey had attended a training session provided by Swindon Carers Centre (which was a smaller proportion than had attended at the time of the first survey) but according to the CHLW herself, the hospital had been on red alert for a long period of time and staff were not being released for training. In Barnet, only 20% of staff who responded to the survey had attended a training session provided by the CHDC.

4.4 Identification, Recording and Referral of Carers

4.4.1 The ease with which carers are identified
The majority of staff surveyed in Barnet (62%) found it easy to identify carers but fewer did in Swindon (38%). These figures are very similar to those reported from the first staff survey (60% and 36% respectively). Almost half of those surveyed in Swindon were not sure if they found it easy or not. However, only a small number of staff admitted to finding it difficult to identify carers (three in Swindon – all nurses – and two in Barnet). The Deputy Director of Nursing at GWH thought that staff were generally proactive in identifying carers, as it was supposed to be a normal part of the admissions process. Staff indicated that it was easier if carers identified themselves first and it was made more difficult when carers did not see themselves as carers. As hospitals are stressful environments, carers’ first priority is sometimes to try and get the person they care for home and they may be unrealistic about their ongoing care needs and the level of support required. Developing a rapport with patients and their relatives was seen as important in relation to identifying carers.

“The key is communication.” (Swindon focus group)

It was thought that there was a risk of carers “slipping through the net” but it was also thought to be important not to make assumptions about who is a carer and who is not. In Barnet, the Head of Operations felt that staff were not very good at early recognition of carers but that they were more successful during the discharge process. There were problems, however, with staff making assumptions about what the carer can or will do rather than actually involving them in decisions.

4.4.2 Systems for identifying carers on the wards
In both Barnet and Swindon over half the staff who were surveyed indicated that there was a system for identifying carers on the wards. The majority of the remainder at both sites did not know if there was a system or not. These figures are an improvement on the first staff survey where only 37% in Barnet and 45% in Swindon said that there was a system. In Swindon, systems identified included the Crescendo nursing system, the Kardex, finding out as part of the admission process, asking patients and/or relatives and information sharing in the MDT meeting. In Barnet, staff mentioned the CHDC,
MDT meetings, talking to patients and/or relatives, finding out through the initial assessment and the JONAH discharge system. In the Swindon focus groups, staff indicated that the most likely ways in which carers were identified were in the MDT meeting and through talking to, and getting to know, patients and family members. Some staff felt that there was too much onus on them to do the identifying and they wondered if carers themselves could be encouraged to identify themselves to staff. One suggestion for how this might be done was putting up notices in the main entrance to the hospital or on wards encouraging carers to make themselves known to staff.

4.4.3 Things that help effective identification and recording of carers
There were a number of elements which were thought to help the effective identification and recording of carers. The most important of these were thought to be:

- good communication (both with patients/carers and within the multidisciplinary team)
- good documentation.

Carers identifying themselves was also thought to help as was having good information about what is available for carers. In Swindon, it was felt that having the ‘carer screens’ on the Crescendo nursing system (introduced in April 2009 by the CHLW) was helping with recording but they were thought not to be in the right place on the system (see Chapter 3, section 3.3.2 for more detail). In Barnet, the presence of the CHDC was also thought to help identification of carers.

4.4.4 Things that hinder effective identification and recording of carers
Not surprisingly, staff felt that the greatest obstacles to effective identification and recording of carers were poor communication and poor documentation and/or information systems. Heavy workload was also cited by a number of staff, which led to a lack of time to find out about carers and then record details of them.

“Time, staff pressures, bed crises – to discharge patients quickly may lead to carers’ needs not being considered.”

(Barnet staff survey)

Carers not seeing themselves as carers was also thought to be a barrier to successful identification. The CHLW in Swindon was disappointed with the number of carers that were being identified; there were fewer than they had hoped for. Between April 2009 and January 2010, 38 carers had been identified who had subsequently agreed to share their information with Swindon Carers Centre. Thirty-one carers had also been identified who did not give permission for their information to be shared with the Carers Centre. From August 2009 to January 2010 only seven carers had been referred to the Carers Centre by hospital trust staff and five had been referred by PCT staff. However, two families had referred themselves to the Young Carers’ Service after seeing information on the wards at GWH. The Deputy Director of Nursing at GWH felt that the small numbers of referrals to the Carers Centre in Swindon were partly due to some carers not seeing themselves as carers. The carers’ notice boards on the wards have been changed so that they do not ask if people are carers but ask ‘Do you help someone?’ in order to address this issue.

4.4.5 Where information on carers is recorded
In Swindon, staff indicated that information on carers was recorded in the nursing Kardex, on the Crescendo system, in the medical notes and in the patient information system. Information was also written in patients’ care plans. In Barnet, information was
recorded in the medical notes, the nursing assessment booklet and in the nursing Kardex.

4.4.6 Information available for carers
In Swindon, there has been an increase in the information available to carers on the wards as a result of the CHLW post. There are now carers’ notice boards on all wards, leaflets, information in bedside folders and specific carers’ information on the hospital trust website. In addition, the CHLW distributes the Swindon Carers Centre quarterly newsletter throughout the hospital and it is also available on the hospital website.

4.4.7 Referral of carers to other services
In both Barnet and Swindon, about half of the staff surveyed said that carers were frequently referred to other services from their ward/area and about one third said that carers were occasionally referred. These figures were a small improvement on those reported from the first staff survey where just over a third in Barnet and just over 40% in Swindon said that carers were frequently referred. The referrals were to social workers and, in Barnet, to the CHDC. Carers were also thought to self-refer after getting information off the notice boards or from leaflets and bedside packs.

One physiotherapist in Barnet commented:

“We attempt to refer whenever appropriate, we should probably refer more often.”

The CHDC in Barnet indicated that the number of referrals to the Out of Hospital project was much greater in the second year than it had been in the first year but he was still concerned that getting referrals from staff was a constant challenge. The main reason for this appeared to be a reluctance on the part of hospital trust to agree to the CHDC ‘cold calling’ carers (although they were happy for him to approach carers on the wards) because of the Caldicott rule that would require staff to gain explicit permission from the carer before they referred them to the CHDC. The CHDC felt that this added an extra step for staff who already had limited motivation to refer carers. They would have to speak to identified carers, explain the support service and then make the referral if permission is granted. This may be a lot to expect of busy nurses who see themselves primarily as patient-focused. Competing priorities were also a problem. When the hospital was very busy referrals to the CHDC declined even more – “the difficulty is that supporting carers doesn’t speed up discharge” (CHDC) – hence, if the ward’s priority was to discharge someone quickly in order to free up a bed, they had no incentive to improve support to the carer.

Another factor was the issue of carers who were not from Barnet being excluded from the service provided by the CHDC. The CHDC solved this problem by agreeing to take referrals for all carers on the understanding that he would put them in contact with their relevant Carers Centre. The Head of Operations at Barnet and Chase Farm Hospital felt that although staff awareness of carers had improved as a result of the CHDC, it was still difficult to get staff to refer carers because nursing staff, in particular, focused strongly on the patient and were not trained to look at wider social needs. They simply did not think about carers. The Head of Operations thought that the answer to altering this attitude was training. However, this posed a challenge in Barnet because they have a lot of bank and agency nurses and a high staff turnover.
4.5 Views on Involvement of Carers in the Discharge Process

In both Barnet and Swindon, approximately three-quarters of staff who responded to the survey thought that carers were either always or regularly involved in the discharge process. These figures were similar to those reported from the first staff survey in Barnet but there was a small improvement in Swindon where two-thirds of staff had thought that carers were always or regularly involved in discharge. It was believed that carers should “undoubtedly” be involved in the discharge process because they have the information needed for a safe and effective discharge.

“[Carers] are the key to the care.”

“It gives [carers] the opportunity to say they are struggling.”

(Swindon focus group)

Other benefits of involving carers in discharge were thought to include being able to get background information on the patient if they are confused/unable to communicate, improving the relationship between professionals and carers, relieving some of the stress the carer may have and signposting them to support, avoiding a failed discharge and giving the carer the right to be absolved from their caring responsibilities. Involving carers in discharge was also thought to be an opportunity for education, for example in relation to medication or moving the patient. If carers were not involved they would not feel valued and discrepancies between the carer’s view and the patient's may not be discovered. This potential problem was highlighted by a carer:

“Communication to me was extremely poor. Ward staff contacted the home to arrange [my mother’s] discharge without consulting me. I found out the plan to send her home by accident.”

Suggestions for improving involvement included raising the profile of the carer role, ensuring that staff liaise with carers throughout the patient's stay, involving the CHDC (in Barnet) and improving the communication between staff and carers.

For one carer, the carers' worker had made all the difference:

“[The CHDC] was the only person who has helped us to resolve any problems. The rest of the other organisations have been dreadful.”
Chapter 5
Conclusions

This evaluation of the pilot projects in Swindon and Barnet has shown that, despite facing some significant challenges along the way, the projects have experienced a number of successes in relation to improving the experience of hospital discharge for carers.

It has been shown that it is possible to change key systems so that the identification and referral of carers is improved but this was found to be difficult and also time consuming, particularly if a change in IT systems is required. It proved to be much easier if there were high-level managerial support for carers’ issues, ideally a carers’ champion at executive level. There was also value in having a hospital trust-wide group that had a remit to improve services for carers, as this enabled greater progress to be made.

The direct support of carers by carers’ workers was found to be improved by links being formed with hospital discharge teams and the ability for carers’ workers to attend discharge forums. It was also found to be beneficial for staff to have straightforward referral pathways to the carers’ worker. Practical issues had caused some difficulties in both of the pilot sites and the need for carers’ workers to have a ‘base’ in the hospital was highlighted.

The projects were thought to have been successful in raising staff awareness about carers and carers’ issues. Having Carers’ Leads on the wards in one of the hospitals had contributed to this success but there were difficulties encountered in relation to finding time for carer awareness training. Often the wards were too busy for staff to be released to attend training sessions. Despite increasing awareness, however, there was evidence that some staff were still not clear about the definition of the word ‘carer’. Although staff awareness appeared to have improved in relation to the potential discrepancy between the views and wishes of the patient and those of the carer, there was still a need for them not to make assumptions about the carer’s ability or willingness to care.

Many family members and friends who provide care and support do not identify themselves as ‘carers’. Ongoing work needs to be done to encourage these hidden carers to identify themselves; good communication between ward staff and the families and friends of patients could make a significant difference in this respect.

Heavy workloads and pressure to release beds were found to have a major impact on the capacity of staff to identify, record and refer carers. If questions about carers are built into core systems and processes, such as those to do with admission and discharge planning, then this capacity may be increased. Most staff saw the benefit of involving carers in the discharge process and agreed that carers should be involved regularly and systematically.

This project illustrates the lessons learned with regard to the challenges faced when trying to change systems and people’s attitudes and awareness. In the Key Messages section at the beginning of this report, that learning is being shared in order to support policy makers, PCTS, hospital trusts and carers’ organisations to work with carers to change systems and attitudes. It is hoped that local health services will be helped to benefit patients and their families by recognising the role of carers and supporting carers as partners in care.
Appendix 1 - Results from Second National Survey of Carers Centres

Links with local hospital trusts

Carers Centres were asked whether they had established links with their local hospital trust and 90% (n=26) indicated that they did have some form of link. These links ranged from informal and infrequent contacts, such as “very informal - they will not directly engage with us”, to much more formal integration, information sharing and representation. Where links had been established, these appeared to align closely to some of the aims of the discharge support services which were identified through the first survey in June 2007. For example, in the 2007 survey seven centres (14%) said that their service was intended to improve identification of carers when the person they cared for was in hospital. In the 2009 survey four centres reported involvement in discharge protocols and processes or received referrals directly from their local hospital trust. One of these has established a discharge project within their local hospital trust (with Department of Health funding) which was being piloted at the time of the survey.

In the first survey six centres (12%) felt that provision of information to carers was an important aim. In the recent survey two of the centres reported that they had information stands at their local hospital trust and four centres reported having their own employed Carer Support Workers who worked (to varying degrees) within the local hospital trusts to provide information and support to carers. One centre commented that “if carers are not part of process [i.e. discharge planning] the care pathway can easily break down as the carer is unable to continue to care.”

In the first survey eight centres (16%) reported that one of their aims was to raise the awareness among hospital staff of carers’ issues and the benefits of supporting carers through the discharge process. In the 2009 survey, five centres (17%) reported having representation on various groups and boards associated with carers’ services in their local hospital trust. Groups included carers’ groups, strategy groups, working groups and one centre had a representative who was a board member of the Foundation Trust. In addition, two centres reported involvement in setting up new project work with their local hospital trusts, although no details were provided about the aims of these projects.

One centre commented that “secondary care is a massive area of work” and a total of 12 centres advised that they were struggling to find the capacity and/or resources to do justice to work they would like to do with their local hospital trusts. This was particularly a problem for centres which were located in areas served by large hospital trusts with multiple hospitals but also for centres in smaller areas served by more than one acute hospital because Carers Centre staff then had to build relationships with several hospitals.

Hospital policies and systems

The Carers Centres were asked about the policies and systems which were in place within their local hospital trusts. Responses to these questions demonstrated that (even where links had been established) many centres were not aware of the policies and systems which were in place. A summary of responses is shown in Figure 1 below:
The process which centres appeared to know least about was whether information about carers was recorded on their local hospital trust’s electronic patient administration system. Nearly two-thirds of centres (19) did not know whether there was a system in place; however three of these stated that they were hoping to make some progress with this. Just one of the centres knew that their local hospital trust did have a system for recording carers.

Fourteen centres were unaware of whether their local hospital trust has a Carers’ Charter and/or Carers’ Standards. Of those 15 local hospital trusts which centres knew about, 10 were known not to have these documents and five centres (33%) reported that these documents were in place within their local hospital trust.

In the 19 hospital trusts which centres knew about, the majority of these (13) were reported not to have a Carers’ Leads or Carers’ Champions at Board and/or Executive level, with just six hospital trusts having these roles at Board and/or Executive level.

Nearly two thirds of centres (19) were aware of discharge policies and procedures in their local hospital trust and whether carers were referred to in these. Of these, 16 were known to refer to carers within their discharge policies and procedures. Centres described a variety of ways in which this reference was made. Some hospitals were known to have carers’ information sections/appendices, checklists and information leaflets, while one centre noted that one of their workers sits on the discharge team at the local hospital trust. Despite this apparently positive response to the reference to carers, four centres questioned whether or how consistently these policies were adhered to.

**Information and support to staff**

Centres were asked about how hospitals support their staff in addressing the needs of carers. Specifically centres were asked whether information about the importance of identifying and supporting carers was given to staff at induction or during other training sessions. Of the 14 centres which were aware of induction and training 12 responded to say that their local hospital trust did provide staff with information about carers. However, this was provided by the Carers Centre itself in four hospitals. Four centres...
also commented that despite their local hospital trust offering training, this was often infrequent and *ad hoc*, with one centre explaining that it was often difficult to release staff to undertake the training offered.

Of the two centres which did not know about induction, two were hoping to become involved in this and develop it with the hospital trust in the future.

Carers’ leads are named persons with specific responsibility for promoting awareness of carers and taking responsibility for carers’ issues on their ward or their department. Within the 20 hospital trusts which respondents knew about, just three were known to have carers’ leads on some or all of their wards. Seventeen local hospital trusts did not have this role in place on any of their wards.

In the recent survey 24 centres reported that there were carers’ workers working in their local hospital trust. Most were employed by the Carers Centres themselves, although a small number were employed by the local authority. Several had NHS funding contributing toward the cost of the roles. The number of workers varied from one to a maximum of eight workers being employed in one hospital trust. Some responses suggested that quite formal working arrangements had been established with hospital trusts, while others appeared to have much more informal and flexible arrangements, including the use of volunteers.

Of the four respondents who reported this role as being absent in their local hospital trust, one centre noted that, despite having no fixed sessions, Carers Centre staff do regularly attend the hospital, and another noted that two carers’ care managers were about to be appointed.

**Information to carers**

As mentioned above, in the previous survey providing information to carers was a key aim for a number of centres. In this recent survey one centre stated that there was no information available to carers within their local hospital trust and two centres were not aware of whether information was available or not. However, 26 centres reported that information was available to carers on the wards in their local hospital trust, although six respondents implied that the information was not displayed or updated systematically in all wards. Where centres offered details on who maintained this information, this was most commonly by the Carers Centre staff.

**Carers’ support services and projects**

Of the 29 Carers Centres which responded, 15 were involved in services or projects aimed at supporting carers around the time of discharge. Of these, 13 projects were being run by the Carers Centre themselves, with two centres being involved in projects run by other organisations (one with their local PCT and other voluntary organisations, and another with their local council). Respondents’ definitions of ‘service/project’ appeared to vary widely from *ad hoc* work in the hospital or production of an information leaflet to large scale multi-disciplinary projects designed to change admission or discharge patterns.

Twelve centres described well-defined aims for their service or project, while one centre reported being in the early stages of development with their local council and had not yet agreed aims. For their response to this and further questions about the project, one of the centres referred to a detailed publication relating to their project which had been
produced in liaison with another carers’ organisation. All service/project aims fell within one or a number of the following areas:

- Supporting carers through the discharge process
- Supporting carers in order to prevent unnecessary admission and re-admission
- Establishing support within the hospital itself, particularly in relation to discharge
- Training and increasing knowledge and awareness of carers’ needs amongst hospital staff.

Nine centres cited barriers which they had experienced in relation to their service/project. The most common barrier, cited by five centres, was in establishing a respected and cooperative relationship with hospital staff. Existing hospital systems were also a barrier for three centres which had experienced difficulty with clinical database systems and also in trying to integrate their service with existing systems and processes. Other barriers cited were changes to budgets and national guidelines, communication about the project within the hospital and getting information onto the hospital wards. A few centres said that they had been able to overcome some of these barriers. However, few details were provided relating to how this had been achieved. There appeared to be a general suggestion that simply by maintaining a presence and keeping links, the situation had improved over time.

When asked about what had worked well, ten centres responded with details of benefits arising from their service/project. One centre which had undertaken a wide-scale training and awareness project within their local hospital trust reported that they had seen benefits. However, they recognised the need to reach many more healthcare workers in order to lead to any significant benefits. This centre was struggling to secure funding for the continuation of training from the hospital trust.

Many projects were ongoing but benefits reported to date included the raised profile of carers within the hospital setting, improved partnership working with the hospital trust, success in influencing hospital processes, increased referrals to Carers Centres and improved support for carers.