Nurses as Case Managers in Primary Care: the Contribution to Chronic Disease Management

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Executive Summary

Background

Chronic diseases are the leading cause of illness burden, disability and death across the world. Internationally, it is a policy priority to improve the experience of, and service delivery to, people with long term conditions and their carers through multi-disciplinary models of chronic disease management. Most of these models involve case management i.e. a professional who has responsibility for overseeing and/or delivering the processes of case finding, assessment, care delivery, monitoring and review for, and with, a patient and their family carer(s). Research on the contribution of nurses to models of chronic disease management, and specifically case management, either assumes that it is self evident what the nursing work is and never describe it, or creates new nursing roles which are represented as innovative, without any reference to existing nursing provision. There is currently little evidence available to inform commissioners or service providers as to: a) the extent nurses are undertaking case management roles with patients with long term conditions, b) what factors facilitate or inhibit them taking these roles, c) the impact for service users and their carers or d) the costs to the service if they adopt these roles.

Aims

This study aimed to investigate the contribution of nurses as case managers for people with long term conditions (LTC). Its objectives were to identify the range and types of nurses' involvement in case management and undertake an in-depth description of their contexts, their activities and their perceived impacts from the perspectives of patients, carers, other service providers and commissioners. Uniquely, this study compared and contrasted the experience of patients receiving different types of nurse case management.

About this study

The overall approach of the study drew on the principles of realist synthesis and realist evaluation. The study was conducted in two phases over three years. There were four elements:

Phase 1

An integrated review of the research evidence to establish the evidence for the effectiveness of the nursing contribution to chronic disease management.

An analysis of policy for the nursing contribution to the care of people with long term conditions in England and Wales.

A survey of the implementation of nurse specific policies across England and Wales.

Phase 2

A comparative case study, in three geographically disparate sites, that tracked the experience, quality of life, health status and use of services of patients with long term conditions (and their family carers) receiving one of three types of nurse led case management.

Key findings

Review of the research evidence. The integrated review found that the nursing contribution to chronic disease management could be categorised into three overlapping types of activity: supplementing, substituting for and complementing existing services. When there were specific problems such as fragmented care, lack of continuity in service provision or difficulties in accessing care, the nursing contribution was to supplement other services and thereby improve the overall patient experience. In situations where the aim was to relieve medical workload or try and reduce costs then the nursing contribution was one of substitution. The last type of nurse activity identified was one of complementing other services. This occurred where nurses provided care alongside other services. There were few examples of this type of nursing activity but the primary influencing factors have been the organic, historical, or evolutionary development from within clinical services rather than responses to a single defined problem.

Analysis of policy. The policy review identified ambivalence in UK policy networks about nurse case management models. There was an absence of discussion of existing generalist nursing services, such as district nursing and practice nursing, and the potential for their involvement in case management activities. The Welsh policy documents considered and rejected naming nurses specifically as case managers for people with LTC. In the English policy documents, case management roles were only advocated for nurses holding advanced practice skills qualifications such as independent prescribing or as specialists in a specific condition working alongside a medical consultant led team.

The national survey. The national survey reflected the policy analysis in that there was little activity within Wales while the English centrally monitored targets for numbers of community matrons gave impetus to the introduction of nurse case managers in English PCTs. Despite a relatively proscribed model of nurse case management from the English Department of Health, the survey identified a wide variety of nurse case management

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models and nurse involvement in admission avoidance strategies for people with LTCs in England.

Phase one established that the term 'case management ' was not used consistently to refer to the same types of nursing roles or activities. The range of nurse case managers, the variety of their settings and work relationships was broader than that described before in the UK. The survey identified and confirmed the main groups of nurse case managers in primary care in England as: community matrons, clinical nurse specialists, and district nurses.

The case studies. Through tracking the experience of patients and families in receipt of different types of nurse case management, the case studies were able to describe in detail the similarities, differences, impacts and changes over time of the different types of nurse case managers.

The patients of the community matrons had the highest levels of co-morbidity, but all the nurse case managers' caseloads had patients with equivalent needs. The findings demonstrated that the nurse case managers irrespective of type could all identify that they were undertaking the six elements of case management. However the frequency, the intensity and resulting costs of using all six elements varied between the types of case managers. Only the community matron undertook all elements for all of their patients.

The majority of the patients recruited to the study and frequently also their family carers, were considerably disabled by their conditions. Over the course of the study, all of the patients became frailer and a fifth died. The transition from being a patient who could benefit from case management to that of a patient in need of palliative care could be problematic, threaten continuity of care and create confusion as to who was the nurse case manager, particularly in service delivery models that had a specific disease focus.

The patients and their family carers were experienced users of health and social care services and this informed their judgements about the different types of nurse case management. They valued nurse case management for: a) the nurse's clinical expertise, b) the nurse's assistance in providing continuity of care and acting as intermediary with multiple services and c) the therapeutic effect of the nurse's as psycho-social support. Patient defined outcomes of nurse case management were articulated as: a) increased confidence in managing their conditions, b) acquisition of self management techniques that made their lives easier, c)their (patient and carer) priorities were addressed, d) patient and family carer time and energy was saved and e) having a professional delivering their care who knew their 'story'.

Some patients however who received community matron case management were concerned that it was a form of surveillance. The evidence suggested that some patients and carers asserted their independence by refusing services offered by nurse case managers.

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Nurse case managers in all the models valued their role. While all undertook all the elements of case management, some placed greater emphasis and time on the assessment and referral elements over the monitoring and review responsibilities. There was also evidence of increasing nurse to nurse referrals over the time of data collection, as nursing care was divided into task based care and assessment and monitoring activities. Over the nine months of the study the nurse case managers who were engaging in all case management activities, sought to delegate or refer some of their patients to other nurses i.e. there was progressive disaggregation and dilution of the case management work overtime. It was within the discretion of the practitioner or the service how the case manager role was interpreted.

Case management when carried out by nurses who exclusively undertake this work was expensive. The factors that increased individual patient service costs were hospitalisations and intensive nurse case management contact. This may reflect that the intensively case managed patients were in fact towards the end stage of life. There is substantial evidence that the highest use of health services and thus costs are in the last year of life, irrespective of age. Some but not all of the patients who received intensive nurse case management input reported lower use of other services. This together with the evidence that community matrons had higher rates of referrals to other services raises the question as to whether nurse case managers facilitate access to more services rather than reduce demand on acute and other services.

The list of factors that supported the nurse case managers in achieving their roles with patients reflect key features of any change management strategy e.g. planning of the service, training, managerial support. However four additional factors for these roles stand out:

1. The presence of a mandate to undertake case management activities that was recognised by others who were providing or commissioning services to those patients,
2. A close working relationship (including sharing patient records) with a multidisciplinary team, including the GP or a medical consultant,
3. Advanced clinical skills,
4. Designated and protected time for case management.

Perhaps the last factor that supported all the nurse case managers in their roles was stability and continuity in mandate. It was apparent that for many of these nurses, stability was not recognised as important by their employing organisation. Community matrons were particularly susceptible to their role being redefined and realigned with other services and almost all the nurses, and particularly district nurses identified how organisational turbulence negatively affected their ability to embed their case management services and maintain continuity of care.

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Conclusions

In England nurse case management is a negotiated, context dependent, role. Models of nurse case management that include clinically expert nurses, undertaking all elements of case management are valued by patients and carers but are resource intensive. End of life care is an important component of nurse case management for people with multiple LTCs and their carers. In primary care, nurse case managers benefit from clear organisational links to general practice. Current service delivery models invariably move experienced practitioners away from the patient.

All four elements of the study highlighted how nurses were actively recruited and involved in supplementing for service deficiencies or compensating for other (medical) practitioners.

Case management interventions need to be integrated with other primary care based initiatives. Our study confirmed this need for integration and demonstrated the difficulties nurse case managers encountered when operating without a multi disciplinary (including medical staff) team as support. It also highlighted that nurse case managers with an appropriate mandate can act as a force for integration, continuity of care and effective collaboration between very disparate professional groups and organisations.

The continual experimentation, accompanied by little organisational learning on the characteristics of effective nursing roles, means that case manager roles are difficult to sustain.

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Glossary

Case management- a collaborative process which assesses, plans, implements, co-ordinates, monitors and evaluates the options and services required to meet an individual's needs. Depending on the context of the case management this may be needs related to health, social care, education, and employment.

Care management - a term applied to the work of UK social workers as part of the Local Authority responsibilities under the 1993 National Health Service and Community Care Act (and subsequent legislation). Case management refers to the same processes as case management.

Community Matron –The NHS Improvement Plan (DH 2004) described a new clinical role for nurses in England, known as community matrons. This role was for experienced nurses, with additional advanced practice skills, to use case management techniques with patients, who had chronic diseases and met a criteria denoting very high intensity use of health care. The aim of community matrons was to support the patients to manage their condition, remain in their own homes, and avoid unplanned admissions to hospital.

Chronic Disease - a persistent and lasting medical condition

Clinical Nurse Specialist – a registered nurse with expertise and often a post-registration qualification in a clinical specialty e.g. diabetes. The post holder only works with patients who have that condition.

District Nursing Service – a home nursing service for people who, in the main, are unable to leave their home without significant assistance. The service is available year round but there is local variation in the types of health care provided, the availability during the evening and the extent to which the service is attached or aligned to general practice. The service is organised into teams of registered nurses and often health care assistants, led by a district nurse team leader. Many of these team leaders will have additional district nursing qualifications.

Long term conditions – A term used in English public policy to describe those conditions that cannot be cured but can be controlled by medication and other therapies.

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Acronyms

BP	Blood pressure
CHD	Coronary heart disease
CM	Community matron
COPD	Chronic Obstructive Pulmonary Disease
CNS	Clinical nurse specialist
CHST	Care Home Support Team
DH	Department of Health
DN	District nurse
GP	General Practitioner
LHB	Local Health Board
LTC	Long term conditions
NRES	National Research Ethics Service
MDT	Multi-disciplinary team
NP	Nurse Practitioner
NSF	National service framework
NVIVO	Qualitative research software
PARR	Patients at Risk of Readmission
PCT	Primary Care Trust
PSA	Public Service Agreement
QOF	Quality Outcomes Framework
SHA	Strategic Health Authority

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1 Background and overall study design

1.1 Introduction

The majority of people with chronic, long term conditions manage their own condition however, when the condition is more complicated, or additional health problems occur, professionals from both primary care and secondary services become more involved in their treatment. There is a small group of people with long term conditions who have complex health and social care needs. It is thought that this group benefit when one member from the health team is given the responsibility for ensuring the co-ordination of that person's care. This person is called a case manager or a key worker. It is not clear to what extent nurses are taking these roles, what assists or detracts from them taking these roles and what impact this has for service users and service delivery if they adopt these roles. This study is designed to answer those questions.

This study was commissioned in the spring 2006 following a call from the NIHR SDO programme for proposals considering the contribution of nurses, midwives, and health visitors to chronic disease management in autumn 2004. This study addressed the contribution of nurses as case managers, working in primary care settings, to health service provision for people with chronic diseases.

This chapter provides the background and context before detailing the aims and the research questions. It describes the theoretical framing of the study, detailing the study design and overall methodology. It presents a discussion of the service user involvement before concluding with a plan of the report.

A note about language

Chronic disease and chronic disease management are the terms used by the World Health Organisation (WHO) and by most of the UK country specific central policy documents until 2004. In 2004 the Department of Health for England stopped using the term chronic diseases and started using the term long term conditions (LTC). This term has been used in general throughout this document unless referring specifically to policies or countries that use the terms chronic disease.

1.2 Background and context

Chronic diseases are the leading cause of illness burden, disability, and death across the world (WHO 2005). The negative impact on an individual's quality of life is significant, as is the impact on communities, economies and

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health and social care systems. Estimates in high income countries suggest that between 65-75 percent of direct health care costs are attributable to chronic diseases (Public Health Agency of Canada 2003, U.S. Centers for Disease Control and Prevention 2004, Australian Institute of Health and Welfare 2005,).

Seventeen million adults are estimated to be living with a chronic illness in the UK of which nearly 8.8 million people have conditions that severely limit their day-to-day ability to cope (Department of Health [DH] 2004a, 2004b, DH 2005a). The commonest of these chronic conditions are arthritis and rheumatism, cardiovascular and respiratory diseases (DH 2004a). The presence of one or more of these conditions rises with age (National Statistics Office 2002) and lower socio-economic circumstances (Craig R and Mindell J 2007). Eighty per cent of primary care consultations and two thirds of emergency hospital admissions in the UK are related to chronic illnesses (Department of Health 2004a). As a consequence, UK government health departments have focused on improving chronic disease management as a way of improving patient care and reducing costs (Department of Health. 2004b, 2004c, The Scottish Executive 2003, The Welsh Assembly Government 2005). Initiatives and service re-design for people with long term conditions have high visibility within policies that address public health (DH 2005a), user participation (DH 2003), social care, promoting user choice (DH 2005c) housing and financial support (Department of Work and Pensions 2005). For people with LTC, in different age groups and with named chronic diseases, National Service Frameworks established specific standards and preferred mechanisms of service delivery (DH 1999, 2004d 2005d). The level of specification ranges from the goal of 'seamless', patient-centred care that cuts across the NHS, Local Authorities, Independent and Voluntary sectors (DH 1997.1999,2004c, Scottish Executive 2003, Welsh Assembly 2001, DH, Social Services and Public Safety, Northern Ireland 2004) and the 11 indicators of quality in the National Service Framework NSF for LTC (DH 2005d) to the specifics of public service targets focused specifically on improved standards of service delivery to people with LTC, (DH 2004c) and targets for chronic disease management in the new GMS contract (DH 2004h).

The UK health policy community has drawn on the experiences of the USA where this type of whole systems approach to the management of LTCs (Wagner 1998,Dixon et al 2004) has been endorsed as a means of ensuring continuity of care, improving patient outcomes and efficient management of resources (DH 2004e 2005a, RCGP et al 2004). The UK implementation of these approaches has focussed on a continuum of care that ranges from Expert Patient Programmes (DH, 2001) to disease specific services provided by specialist multi-disciplinary teams (DH 2001a) and case management of people with complex needs and at risk of unplanned hospital admissions (DH 2004d, 2005a). In all the UK countries, the overarching policy frameworks draw on Wagner's model of chronic disease management (Wagner et al 1996). This model stratifies populations by complexity of condition(s) and requirements for health interventions, emphasising the need for prevention and enhanced self-care for the majority and improved

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case management for the minority with multiple complex conditions. At level 1 people with LTC are characterised as living with and self-managing their condition. At level 2 people with LTC are characterised as at high risk from their condition, who are receiving active care management from multi-disciplinary teams. At level 3 people with LTC are characterised as having unstable and/or complex conditions that require proactive case management by a designated key worker.

The concept of case management is not new and in the UK has roots in social care (Challis & Davies 1986) and community mental health care (Department of Health 1994). In the UK, case management was adopted in the early nineties, and renamed 'care' management, as the centrepiece to the national changes to the organisation, provision and funding of the public provision of community care. The introduction of care management was supported by the evidence from demonstration projects (Challis et al 1991) in addressing the pressing issues of service fragmentation, incoherent planning and delivery and cost containment (Griffiths 1988). The core elements of any case management activity are: identification of individuals likely to benefit from case management, assessment of the individuals' problems and need for services, care planning of activities and services to address the agreed needs, co-ordination and referral to implementation of the care plan, and regular review, monitoring and consequent adaptation of the care plan (figure 1). There are two main models of the case manager role: case managers holding budgets to finance care packages for the user, known as the brokerage model , and case managers providing services themselves and co-ordinating other agencies' services, known as the key worker extension model (Beardshaw and Towell 1990). These models have been called respectively a brokerage model and a key worker extension model.

Demonstration projects providing different forms of case management across this spectrum of LTC were developed in England from 2003 onwards e.g. Pfizer, Kaiser Permanente, Evercare, Unique Health (Matrix 2004; Boaden et al 2005). At the point of the commissioning of this study none of these had produced final evaluation reports.

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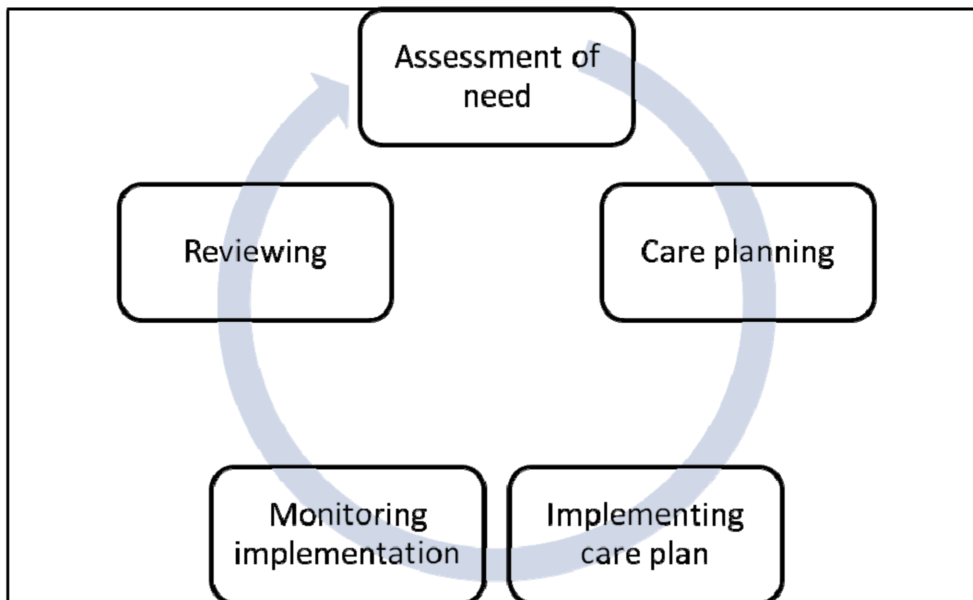

Figure 1. The case management cycle following identification of the individual

1.3 The nursing contribution to chronic disease management

Nurses have always been involved with patients with LTC through providing health promotion, patient teaching, direct nursing care and medical treatments. There has been an expectation that nurses will take an increasing role in the care of people with LTC and complex needs (Wanless 2004). In England, this was acknowledged through the endorsement of chronic disease management (CDM) as one of the three core roles of primary care nursing (Department of Health 1999, 2001b). New conceptual models for CDM promoted more proactive approaches by nurses to enable people with LTC to self care and where there are more complex needs to avoid unplanned and unnecessary use of acute services. The individual models of care delivery for LTC that involve a nurse contribution can be explicit, as in the clinical nurse specialist for patients with a chronic disease (DH 2004c, 2005b), or as part of a more generic role that provides care on the basis of location (e.g. in the patient's home, the GP practice or in hospital). Research on the nurse contribution to chronic disease management in the UK has a thirty-year history. It has focussed on the process and outcomes for particular patient groups (e.g. Kratz 1978, Stuck 1993, Gagnon et al 1999, Leveille et al 1998, Wagner 2000, Goodwin et al 2003, Algera et al 2004) and compared the care provided by nurses with other specialist nurses or disciplines such as medicine and social work (e.g. Ross and Tissier 1995, Forbes et al 2003, Rafferty et al 2005, Walsh et al 2005). The findings from these studies demonstrate the complexity of the

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care provision, variable outcomes, and the methodological challenges in distinguishing the effects of the nursing contribution from those of medicine and social care (Litaker et al 2003, Hutt et al 2004, Ross and Harris 2005). Nevertheless, studies suggest that two key factors in *how* care is provided are: a) the expertise of the nurse and b) the orientation of the nurse to the acute hospital or to primary care. Studies that have compared nurse led care with other discipline led care for different patient groups with LTC provide mixed evidence as to whether nurses achieve equivalent or better outcomes. Invariably, the studies lack detail about the nurses' contribution, their exact roles, activities and the expertise used (Cullum et al 2005, Bodenheimer and Macgregor 2005). Such details are often missing or subsumed in overall descriptions of the patient and resource outcomes of the study.

1.3.1 The example of nurse case management

Although case management is not new there is a renewed interest in this approach for people with LTC. In particular, demonstration projects in the USA have evoked interest in nurses using case management techniques (Hutt et al 2004). In England, this interest has been accompanied by the introduction of a new role, community matrons, to support people in the top strata of complex LTC using case management techniques (DH 2004c). A national target was set for Primary Care Trusts (PCTs) to have 3000 community matrons appointed by 2007, later extended to 2008 (DH 2004f).

To date, four delivery models of nurses using case management techniques can be identified:

- Cultural tradition and focus of their discipline and/or clinical speciality e.g. district nursing, rehabilitation nursing (Bergen 1994, Goodman 1998,Long et al 2002, Evans et al 2005)
- Through statutory based systems led by social services/social work/adult services (Challis 1991, Weiner et al 2003)
- As specialist posts for the case management of people with multiple conditions (Woodward and Colin-Thomé 2001, Boaden et al 2005)
- As clinical specialists with dedicated case loads that focus on supporting people with particular diseases and/or conditions (Blenkinsop et al 2003, Forbes et al 2003).

The literature is weak in specifying the extent to which nurses are involved in each of these models; how they are sustained or if particular, elements are more crucial to improved outcomes than others. Factors such as levels of user involvement, types of nurse training, preparation and experience, discrete areas of nursing responsibility, types of clinical and operational support and inputs from other disciplines are all likely to have a bearing on outcomes for people with LTC and their carers (Drennan and Goodman 2004, Murphy 2004,Gask 2005). It is also not documented what clinical and financial authority the nurse requires to fulfil these roles to their maximum advantage and the organisational relationships, for example with medicine and social care services, that underpin success. An interim evaluation of one model, Evercare nurse led case management for people at risk of admission

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to hospital, highlighted how the context of care and issues around level of training, skill mix and role recognition affected practitioners' ability to fulfil their roles (Boaden et al 2005).

In addition to these professional and organisational questions surrounding the nursing contribution to care, a number of questions remain unanswered from the patient and user perspective. There is no linear link between the presence of a condition that can be labelled 'chronic' and the actual need for health or social care (De Lepeleire and Heyman 2003). A publication from the Long-term Medical Conditions Alliance (LMCA 2004) suggests that patient priorities may differ from those of NHS managers and clinicians and that the concept of chronic disease management initiatives is alien to some older people's views of themselves and their independence. Indeed this organisation observed that the numbers of LTC initiatives are overwhelming (Pink 2004). It may be that it is families who appreciate these approaches more than the individual who are targeted (Drennan et al 2003). How people understand and judge the experience of chronic disease management and the involvement of different types of professionals are largely unknown and recent evaluations of the Expert Patient Programmes indicate that patients and professionals can have widely differing views of the efficacy and value of a self care approach (Wilson 2005).

These debates can also be framed by the literature on the introduction of innovation and the dissemination of best practice in complex adaptive systems (Dawson 1996, Rogers 1995 and Greenhalgh et al, 2005) as the next section outlines.

1.4 Theoretical framing

The study is framed by theories of: a) system models of CDM described above in section 1.3, b) the introduction of innovation in complex adaptive systems (Dawson 1996, Rogers 1995; Greenhalgh et al, 2005) and c) the organisation of health care work between and within occupational groups in primary care.

The organisation of health care work has always been divided between professional groups. These divisions are not rigid. They shift over time and are shaped by the context. Current human resource and workforce policies in the NHS argue for the blurring of boundaries of work roles between and within professional groups, role re-design, and increased use of staff with different types and levels of skill in patient care delivery (DH 2002b, 2004i). Legislation has supported these policies, for example, in permitting suitable qualified nurses and allied health professionals the right to prescribe prescription-only medicines (Health and Social Care Act 2001).

The relationships between and within professional groups in the division of health care work has always been characterised by hierarchies, gendered divisions into occupational groups, diverse forms of autonomy and different levels of authority and power (Stacey 1988, Elston 1991, Davies 1995). In primary care general practitioners (GPs) are seen as central players in the division of work (Peckham and Exworthy 2003). However, the division of

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health care work in primary care is more complex than that provided within a single organisation such as a hospital. In the UK the historical divides between the publicly funded services of general practice, community health services, and local authority social services (now termed adult services) are structural elements of that complexity (Webster 2002). Recent policy is creating new forms of organisational partnership and service commissioning that addresses some but not all the structural divides (DH 2000a, 2002a, 2005a, DCLG & DH 2007). At the patient care level in primary care there is a long history of a) advocacy of closer collaborative working between professional groups (Rivett 1998) and b) descriptions of the inadequacies and challenges of inter-professional working (Peckham and Exworthy 2003, Iliffe 2008). The themes of the NHS human resource and workforce polices in role re-design, blurring boundaries between professional groups and introducing skill mix in patient care delivery teams add new dimensions to the division of work in primary care. Evidence of this change comes in examination of the primary care nursing workforce which has changed significantly in the past ten years with many more staff grade registered nurses and health care assistants and a decline in specialist trained community nurses (Drennan and Davis 2008). Estimates suggest that in the UK nurses could undertake anything from 17- 70% of general practitioner work (Jenkins-Clarke et al 2001,Kernick and Scott 2002, Wanless 2002). The substitution of GPs by nurse practitioners in primary care produce good levels of patient satisfaction and equivalent care to GPs but the evidence is unclear as to whether they are cost effective (Laurant et al 2005). The continued growth of practice employed nurses in the UK (Drennan and Davis 2008) suggests GPs are in support of the transfer of work to nurses, however, there is a view that this support does not extend to nurses who are not directly employed by them (Sibbald 2000). The ambivalence of GPs to the application of Taylorist working practices (Taylor 1911) through forms of soft bureaucracy (Courpasson 2000) is well documented (Iliffe 2008). At the same time there is also evidence that primary care nurses employed by community services are reluctant to take on what they see as medical roles, for example, medication prescribing. A study of nurse prescribing in England found that general practice employed nurses prescribed medicines most frequently and in greater numbers than those employed by community services (Davis and Drennan 2007). One explanation is the heterogeneity of the nursing workforce and the existence of sub-groups with very different attitudes to nursing work. While sometimes labelled differently, these sub-groups have been identified as a) those who view themselves primarily as workers earning their living, focusing on tasks (blue-collar workers, the generalists, the utlizers), b) those who view themselves as professionals, are skills focused (the white collar professionalisers) and c) the nurse managers removed from clinical practice and immersed in managerial cultures (Habenstein and Christ 1955, White 1985, Carpenter 1993, Traynor 1999).

Against this backdrop of the Taylorist influenced approaches to human resource management and the jostling between and within professional groups, new and emerging features of health care are likely to add additional elements to the dynamic of the division of work. These include:

- A growing demand for health care from a population that is increasingly knowledgeable and assertive,
- Policy emphasis on increasing the delivery of health care outside the acute sector (DH 2006, 2007a, 2008b),
- Pilots of NHS personal health budgets (DH 2008b),
- The increased use of remote and assistive technologies in health (DH 2006, DH/Longterm Conditions 2009),
- General practice based commissioning (DH 2008a)
- New initiatives to separate community health service delivery from commissioning, to create opportunities for new forms of providers and to develop quality metrics, quality accounts and commissioning currencies relevant to community health services (Department of Health 2008b, 2009a, 2009b),
- Potential restraint in the levels of public finance available for health and social care services in the wake of the economic recession of 2009.

1.5 The aims and objectives of the study

This study was designed to determine the extent and impact of the nurses' contribution and its place within complex health and social care networks delivering services to people with LTC, in order to inform those engaged in decision making for service organisation and delivery.

The aims of the study were directly informed by the funding body's research brief. They were:

- To inform the NIHR SDO Programme about the types and impact of the contribution of the nurses as case managers in different models of chronic disease management,
- To make recommendations about how these contributions can be maximised and sustained,
- To help disseminate findings as widely as possible to service users, service-planners, commissioners and providers of services for people with LTCs as well as to those responsible for the recruitment, education and development of the nursing workforce.

The study objectives were to:

1. Describe and classify the roles of nurse case managers in models of chronic disease management
2. Identify the drivers that have stimulated the development of models of chronic disease management that involve nurses as case managers
3. Describe the range and type of nurse case management models and the ways that they involve service users and carers
4. Evaluate the impact of nurses' contribution to the experiences of patients and carers
5. Identify the factors that enable nurse case managers to contribute most effectively to successful outcomes of care
6. Evaluate the impact of the nurse case manager's contribution upon the cost, quality, effectiveness, and organisation of the care provided
7. Identify the factors that sustain the models of nurse case management over time

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The research questions for the study can be summarised as "what type of case management, delivered by which types of nurses, in what types of settings are effective, for which patient's?

1.6 Study design and methods

The overall approach of the study draws on the principles of Realist synthesis (Greenhalgh et al 2005, Pawson et al 2004) and realist evaluation (Pawson and Tilley 1997). A research approach which places importance on the context as well as the process and interventions (mechanisms) and outcomes in order to be able to demonstrate not only the outcomes but how they have been achieved. The design captures context at a macro, meso and micro level with three strands of investigation these are:

- Macro level analysis: a review of research and policy (England & Wales)) on NMHV contribution to chronic disease management
- Meso level analysis: A survey to establish at the service organisation and delivery level how nurses contribute to chronic disease management across England and Wales
- Micro level analysis: an in-depth analysis and comparison of the process of care and outcomes of the nursing contribution to patients with long term conditions from the patient perspective using a comparative case study methodology (Yin 1991) in three study sites.

The findings from the macro and meso elements of reviews and survey provided an organising framework for the empirical, multiple case study phase of the project as well as providing the basis for comparison with the in depth findings from phase II.

In summary the study objectives were met by the different elements as illustrated by Table 1. The detail of the methodology of each phase is presented in the following chapters: chapter 2 the integrative review, chapter 3 the policy review and survey and chapter 4 the comparative case studies.

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Table 1. The study elements in relation to the study objectives

	Study Element		
Study objective	Integrative Review	Policy Review and Survey	Case Study
1	✓	✓	✓
2	✓	✓	✓
3		✓	✓
4	✓	✓	✓
5	✓	✓	✓
6		✓	✓
7			✓
8			✓

1.6.1 Ethical review and research governance

Each phase of the study had separate ethical and research governance considerations. The entire study was conducted in line with the ethical considerations for social research (Social Research Association 2003). The survey phase was considered by the NHS Central Office for Research Ethics and deemed to be service evaluation, which does not require NHS ethical review. The survey phase met the ethical review requirements of University College London. The case study phase was reviewed by an NHS Local Research Ethics committee and given a favourable review. NHS research governance permissions were obtained from each of the organisations participating in the case study element.

1.7 Service user involvement

The study lead for patient and public involvement (SB) was also a member of the management group. The study design included a User Reference Group of up to ten members, whose role was to advise on the research process and give an insight into the data analysis. This approach has been used successfully in a number of previous studies (Smith et al, 2005, 2008).

Service users were recruited from a number of different voluntary organisations, which represent people with long-term conditions or carers. These included : Parkinson's Disease Society, Age Concern, Long-term Medical Conditions Alliance (LMCA), Arthritis Care, The Stroke Association, INVOLVE, and the London Dementia Centre. The recruitment strategy involved contacting lead people within the organisations to advertise, as appropriate, via newsletters and websites our request for volunteers to join the user reference group. Group members were required to have some previous experience of being a patient representative on a committee, but previous research experience was not required. An information sheet outlining the study, the aims of the user reference group, what participation involved, was sent to all those who identified as potential reference user group members and details of the honorarium offered in acknowledgement

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of their time. Interested parties were contacted by the researcher and invited to the first user reference group meeting. In total eight service users were recruited to the first group meeting, most of whom had long-term conditions themselves or were carers for people with long-term conditions.

1.7.1 Role of service users

The aim of the reference group was to ensure that the study incorporated the patient or service user and carer perspectives and experiences in its design and execution. Service users and carers were paid travel expenses and a flat fee for attending meetings. As part of their role they were asked to do the following:

- Advise on research topics of importance to patients in the literature review, and the relevance to patients of the themes identified by the researchers.
- Comment on the wording and content of patient information booklets, questionnaires, interviews, and patient diaries.
- Give their views on case management, familiarity of the term and its meaning to people with long-term conditions.
- Suggest the best ways of communicating the research findings to patients and their representatives.

The user reference group met four times over the course of the study. Full details are given in Appendix 1. These meetings were chaired by the study lead for public and patient participation. The aim of the first meeting was to introduce members to the research team, each other, and the study as well as receive their views in order to shape data collection in the case study phase. There were very detailed discussions of experiences and the public understanding of case and care management as it applies to people with long term conditions. At the second meeting, the group were given an overview of the data from the survey and invited to contribute to the analysis. The remainder of the meeting focused on detailed discussion of data collection tools that would be used with older people in the study and the benefits and challenges of different types of diary-keeping. The third meeting focused on analysis of the experiences of three older people, receiving case management as part of the study. Three anonymised patient vignettes were used in conjunction with a short set of issues to consider (see appendix 1). The user reference group was asked to give their interpretation of these examples of nurse case management to aid the study team's analysis of the case studies and to highlight any gaps in data collection. The contributions from these discussions fed back into the research process through changes to some data collection tools and paperwork. Service users' perspectives on the study and their own experiences of nurse case management were also documented. At the final meeting service users were presented in more detail with the experiences of two different patients who had been 'case managed' for at least nine months. They were asked to comment on the patient experience; whether or not the presentation of the data made sense; if any of the findings were surprising; and how typical or atypical the scenarios seemed to them. The

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group also discussed how the study findings might be communicated to service users, carers and other lay groups.

Regular communication about the study was maintained through email, phone calls, and letters, with meeting papers being sent out in advance. The management group met to plan each user reference group meeting, paperwork was kept to a minimum to make it as accessible as possible for members. Specific feedback from the user reference group meetings was presented in newsletter format, highlighting the main discussions from each meeting (see Appendix 1). Given the time lapse between each meeting, this communication facilitated on-going involvement and was highly valued by group members.

1.7.2 Reflections on the user involvement process and involvement

Involving services users and carers added to the richness of the study, especially through their questioning of the definitions of some of the underlying ideas and concepts on which it was based. They provided an alternative commentary that was not 'contaminated' by policy or previous research, forcing the research team to clarify assumptions and re-orientate the approach of the study to be one about people and not patients that are high users of NHS resources. Such involvement may be a form of good governance of research in that service users and carers can be the 'personal memory' of a study, with their experiences of numerous and multiple initiatives, and they can also be the 'conscience' of a study, reminding the research team of the ultimate purpose of the enquiry – the improvement in people's quality of life. These perspectives were especially insightful in this study in relation to the service users' interpretations of the concept of 'case' and 'care' management. For example, some service users viewed the term negatively in that referring to someone as a 'case' was a way of depersonalising them. It was thought that for most people the term 'care' was more meaningful than 'case'. Case management was seen as being exclusively health or medical related, it implied passivity, and possibly involving 'having something done to you'. It was equated with having a problem and involving one episode or event. Care management was seen in a more positive light. It was associated with a nurturing, gentler, and more inclusive approach, not exclusively medical and more personalised. The focus on providing case management for older people who had frequent admissions to hospital was perceived to be too narrow; the group thought that there were others who could equally benefit, but may have high levels of contact with other services.

The group were particularly interested in the different roles of the community matron and the nurse specialist. Although both may act as case or care managers, their referrals come from different sources. Data was presented for discussion that appeared to show that there may be some potential for a clash of views between GPs and nurse specialists where the latter were working with hospital consultants. The group thought this might leave patients worse off than if they did not have a nurse specialist.

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The examples of case management that were discussed in the meetings were perceived by the group as atypical examples of older people with long term conditions living in the community. They were surprised by the high level of resources and input that they received, especially those who were being case managed by the community matron, who they referred to as 'the lucky ones'. It was thought that this high level of resources was probably the result of 'postcode lottery'. This was not typical of their own experiences as patients and carers, a number of who had acted as their own case manager to coordinate their care or that of their relative.

The impact of having a 'family' carer was discussed on another occasion when it was surmised that having a carer to advocate for a patient might mean that more services were received. Alternatively, patients with identified carers might not receive case management: the carer being seen as a substitute for professional help.

Although service user involvement was invaluable to the study, it also presented a number of challenges. Reference user group meetings stimulated much debate and discussion, but at times it was difficult to balance the needs of the study with the issues which individual service users wished to discuss. For this study, one of the main difficulties was maintaining the reference group membership and attendance at meetings. As already mentioned, most service users had a long term condition themselves or were carers for someone with one. On a number of occasions members could not attend as the person they were caring for was unwell. Sadly three members died over the course of the study. A further two members joined over the course of the study, but recruitment was harder at later stages of the study. Although the user contribution was invaluable to the study process, it was limited in that any major changes to the data collection tools or paperwork were restricted by the ethics processes and the study timescale.

The experiences gained from working with the study user reference group will facilitate the incorporation of a similar model of user involvement into future research proposals, where appropriate. In view of the difficulty in maintaining the membership of the group, in any further research, we would recommend recruiting a larger number of service users and carers at the outset, to allow for natural attrition over the study period. We might also consider having smaller groups in the study sites to debate matters such as the importance of the local context.

1.8 Organisation of the report

This chapter provides the overall context and scope for the study. Chapter 2 and 3 presents phase 1 of the study. Chapter 2 reports on the findings of the integrative review of the literature, which addressed the question: What is the evidence on to the effectiveness of nurse case management, in what contexts and by which nurses with what type of patients? Chapter 3 describes the macro and meso level elements of the study which investigated the policy perspective on the role of nurses in chronic disease management in England and Wales, followed by a survey of the

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implementation of policies and in particular the emerging role of nurses as case managers. Phase 1 was undertaken in 2006-2007.

Chapters 4-10 report on phase two of the study. This was a comparative case study of different types or models of nurse case managers managing people with long term conditions, examined through the experiences of their patients over nine months. It includes an economic analysis. This phase of the study was undertaken from 2007-2008.

The report concludes in Chapter 11, which draws the phases of the study together in a discussion, conclusions, and recommendations.

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2 Evidence from research

This chapter reports on the literature review and evidence synthesis that contributed to the overall study aim of:

- Investigating the types and impact of the contribution of the nurses as case managers in different models of chronic disease management.

The specific questions that the literature review and synthesis addressed were:

- What types of service delivery models for people with long-term conditions do nurses contribute to?
- What is the evidence of impact and cost of the nursing contribution, and specifically nurse case management, in different types of service delivery models for managing the treatment and care of people with long-term conditions?
- What is the evidence that different types of nurses (i.e. groups of nurses working to different objectives, nurses with different types of education, training, and experience) achieve noticeably different outcomes for their patients and the organisations they work within?

In addition the review aimed to: identify gaps in the literature, identify any methodological problems raised by the literature and to contribute to the organising and conceptual framework for the fieldwork phase of the study.

The chapter provides a summary of the review and synthesis approach, the literature reviewed and an overview of the evidence. It concludes with a synthesis of the findings; highlighting the recurrent themes from an organisational and systems perspective.

A full report of the narrative review led by Cherill Scott, which informs this chapter, is available separately (Scott 2007).

2.1 Background

Nurses have always been involved in the health care of people with long term conditions through providing health promotion, patient teaching, direct nursing care, and medical treatments. There is an expectation that nurses will increasingly take responsibility for the primary health care for people with LTC and complex needs (Wanless 2002). In England, this is acknowledged through the endorsement of chronic disease management as one of the three core roles of primary care nursing in England (Department of Health 1999, 2001). The nurse’s contribution is consistently identified as; identifying need, achieving continuity of care, co-ordinating service input and reviewing care for people with long term conditions (DH 2001b, Drennan and Goodman 2004, DH 2005 a, b, c). Studies that have compared nurse led care with other discipline led care for different patient groups with LTC provide mixed evidence as to whether nurses achieve equivalent or

better outcomes. Invariably, the studies lack detail about the nursing contribution, their exact roles, activities and the expertise used. (Cullum et al 2005, Bodenheimer and Macgregor 2005). Nurses are not homogeneous in their education and training, their prescribed work roles, their professional experience, the objectives of the service or the team they work within, or their position in health care organisational hierarchies. It is these elements that are often missing or subsumed in overall descriptions of the patient and resource outcomes of studies. This review aims to inform this discussion and consider whether there is evidence that different types of nurses i.e. groups of nurses working to different objectives, nurses with different types of education, training and experience achieve noticeably different outcomes for their patients and the organisations they work within. The review element of the project focused on the nursing contribution within models of case management for people with long term conditions.

2.2 Method

The context dependent nature of nursing work, particularly in primary care settings (Hockey 1979, Goodman et al 2003, Sibbald et al 2006, Iliffe 2008) suggests that is impossible to understand what nursing achieves without considering the particular systems they work within, how the patients they care for are identified and how they assume responsibility for their work. Consequently, the overall approach of the review was informed by the principles of realist synthesis (Pawson et al 2004, Greenhalgh et al 2005). This approach was developed in response to a methodological requirement for a synthesis method that was more analytical than conventional narrative reviews and could deal with management and service delivery methods; an area that cannot be addressed by the conventional approach to clinical treatments exemplified by randomised, controlled trials. Pawson and colleagues argue that the generalisation of research findings cannot take place through the aggregation of quantitative findings, but through the development of theories that underlie social interventions. It offers an 'explanatory, rather than judgemental focus' and emphasises the critical importance of context to understanding the implementation of new interventions. For this review, the intervention under discussion consists of the establishment of services that are directed and/or delivered by nurses for people with long-term conditions, - an 'organisational intervention' according to the framework of interventions published by the Cochrane Collaboration Effective Practice and Organisation of Care (EPOC) Group (Bero et al 2007). The overall question addressed was: 'which form of the intervention (i.e. nurse-led/ nurse delivered services), delivered by whom, is likely to be most effective for client groups and at what cost?' The underlying assumptions that informed the review were:

- The management of chronic illnesses and other long term conditions is a social and political issue, and not purely a health care concern.
- Strategic approaches to (or models of) the management of long term conditions will reflect developments in health technologies, the priorities of governments and the changing aspirations of nurses and recipients of services.

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Nurses, possess (or can easily acquire) the knowledge and skills needed to make them key players in policy implementation.

- Nurses, work collaboratively, but make a distinctive contribution to service delivery that can be identified and evaluated.
- Some nurse-led services can substitute for services traditionally provided by doctors.
- Nurse case managers (including community matrons) can reduce emergency hospital admissions and the length of hospital stay (and therefore reduce costs to health services), and coordinate the delivery of individualised care plans for high-risk patients.
- The contribution and effectiveness of nurses, midwives, and health visitors are determined by local, contextual factors.

This approach allows for the inclusion of evidence from a wide range of sources: experimental and quasi-experimental trials through to grey literature. The sampling strategy is refined in the light of emerging data; in this it diverges from a conventional systematic review.

Inclusion and exclusion criteria

The review focused on care delivery services for people with long term conditions in which nurses play a key and/or leading role. In order to appraise the relevant research evidence on the effectiveness of nurse-led, or nurse delivered, interventions it was agreed to include papers that:

- Were in the English language only
- Were published within the ten year period January 1996 – September 1 2006 (with the exception of any earlier key texts)
- Had a nurse or health visitor contribution as a key element of the research design
- Used a sufficiently rigorous design to evaluate the effects of the above contribution on the outcomes of care.

The exclusion criteria were:

- Studies that involved people with enduring mental health problems as a primary diagnosis
- Studies that focused exclusively on children and/or young adults with long-term conditions.

The narrative review also included papers that provided different perspectives on nursing interventions e.g. papers reporting the views of patients and carers, and the wider socio-political contexts within which nurses are working e.g. Department of Health policy papers. This chapter focuses on the research evidence and a full account of how these subsidiary resources were used is provided in narrative review by Scott.

Initial searches

A systematic search of key electronic databases was undertaken in collaboration with an information scientist. This generated an initial library of 15536 references, which were stored using the EndNote bibliographic

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software package. An initial screening exercise identified papers that could be excluded.

A second, more focused screening process looked at abstracts to select research-based papers that satisfied our broad inclusion criteria. The remaining references were then scrutinised more closely using the agreed selection criteria. During the course of the review, additional relevant papers were identified from citations or recommendations from colleagues. This produced a final Endnote 'library' of 1,465 potential papers for review.

Data extraction

A template for extracting data from individual papers was adapted from that used by EPOC (Effective Practice and Organisation of Care Group) Bero et al 2007). It included such categories as: study design, type of intervention, purpose of intervention, details about the characteristics of study participants, study setting, health care system, and outcomes. A separate template was developed for extracting data from systematic reviews. In order to test this method, data was extracted from systematic reviews and papers relating to three specific long–term conditions: epilepsy, rheumatoid arthritis, and Parkinson's disease. A small sub-sample of papers was read by one of two independent reviewers. Information synthesised from the early data extraction exercises was used to inform the steering group's plans for the empirical elements of the project. The level of evidence demonstrated in a research study was recorded on the extraction form, using the categories suggested by the Centre for Reviews and Dissemination (CRD), University of York (Khan *et al* 2001). The levels of evidence were:

Level 1 = experimental studies

Level 2 = quasi-experimental studies (experimental without randomisation)

Level 3 = controlled observational studies (cohort studies, case=control studies)

Level 4 = observational studies without controls (qualitative, case studies, before-and- after)

Level 5 = expert opinion, consensus

An additional refinement of the inclusion criteria was made, on the advice of the study management group, at this point to make the review more manageable. Papers were included relevant to the following five 'tracer' conditions: asthma, chronic obstructive pulmonary disease (COPD), epilepsy, rheumatoid arthritis, and Parkinson's disease. In addition to these five conditions, papers were included which focused on nurse case management as a specific organisational intervention. The case management papers included people with some conditions outside our five categories, but were most likely to focus on vulnerable older people with co-morbidities.

The early stages of the review had suggested that themes and models of service delivery were recurring independently of condition; this convinced

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us that, despite imposing the above constraints on our data collection, the approach would achieve a sufficiently broad evidence base for analysis.

2.3 Review findings

2.3.1 Papers included in the review

Data was extracted from a total of 192 relevant papers, including systematic reviews, research-based papers, audit reports, policy documents, scholarly discussion papers, and book chapters. The overall time taken for developing the database and reviewing the selected literature was April 1 2006 – May 31 2007. The final review included a total of 114 research or audit based papers (Table 2): of which nurse case management formed the largest category (Table 3). The majority of studies were conducted in the UK and North America (Table 4).

Table 2. Papers in the review by research category

Type of research evidence	Number of papers
Randomised controlled trials	43 (36 trials)
Qualitative studies	17
Systematic reviews	16
Before and after studies	13
Surveys	11
Non-randomised controlled trials	7
Audits of service	7
Total	114

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Table 3. Papers in the review by medical condition and nurse case management

Trace long term conditions and nurse case management	Number of papers retrieved
Asthma	19
Chronic Obstructive Pulmonary Disease(COPD)	22
Epilepsy	16
Parkinson's disease	4
Rheumatoid arthritis	18
Nurse case management studies include additional diagnostic groups: congestive heart failure (6 papers), diabetes (5 papers), older people with no reported primary diagnosis but many study participants were reported to have co-morbidities (16 papers).	35

Table 4. Country of origin of study papers

Country	Number of Papers
United Kingdom	64
USA & Canada	24
International/mixed (as in systematic reviews)	16
Europe	5
Australia & New Zealand	4
Asia	1

2.4 Research on the nursing contribution by service delivery setting and disease type

This section explores the evidence of different types of care delivery system in which nurses have a leading role using the research concerned with the five 'tracer' conditions. The majority of these papers reported on UK studies, unlike the mostly North American studies of nurse case management reported below.

The service delivery model of nurse-directed clinics was the most frequently studied organisational intervention that addressed improving the management of long-term conditions (LTCs). These interventions were in both hospital and primary care settings and were staffed by either clinical specialist nurses or (general) practice nurses. The evidence is now considered by service delivery setting.

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2.4.1 Secondary care settings

The papers included in this section included reviews on nurse led in patient interventions(Griffiths et al 2004,Rice and Stead 2004), disease management (Egan et al 2002, Morice and Wrench 2001 and Sitzia 1998)and hospital out- patient clinics (Warren 1998,Hewlett et al 2000, 2005, Levy et al 2000, Ridsdale 2000,Temmink 2001,Tijhuis et al 2001,van der Hout 2003 ,Kirwan et al 2002 , Pope et al 2005). In addition, there were a group of trials that sought to compare directly the outcomes of established nurse-led outpatient clinics with those of usual (medical) care (Hill et al 1994, 1997, 2003, Sharples et al 2002, Arthur and Clifford 2004).

Only two studies investigated whether nurses with different levels of education and experience achieved different outcomes for their patients. One randomised follow-up study (Reynolds et al 2000) compared a nurse-only clinic with a combined nurse/consultant clinics and Ryan (2006) compared ‘usual’ and ‘expert’ nursing care in a rheumatology outpatient clinic.

Even where there was evidence that nurse led interventions by nurses were effective there was limited discussion of the process of care (Griffiths et al 2004). The literature on nurse directed outpatient clinics emphasized the nursing contribution to the organisation of services as as a) addressing known gaps and deficiencies in service delivery, b) relieving pressures on outpatient medical teams, and c) strengthening the links between primary and secondary care through providing improved continuity of care or supplementing the services provided by doctors (Warren 1998; Temmink 2001; Tijhuis et al 2002). The (successful) nurse practitioner trial reported by Sharples et al (2002) is the sole example of a straightforward substitution role, where tasks formally performed by doctors were transferred to the nurse with the intention of addressing workforce pressures. The foci of the nurse interventions in these papers were wide ranging including: improving access and reducing use of inpatient services (Warren 1998,Hewlett et al 2000, 2005, Kirwan et al 2002), managing exacerbations (Pope et al 2005), and providing ongoing patient education in self care and symptom control (Levy et al 2000,Ridsdale 2000,Temmink 2001,Tijhuis et al 2002,2003,van der Hout 2003).

In terms of impact on patient-reported outcomes, many of the studies reported either statistically significant outcomes, or else trends, which suggest the positive impact of nurse-provided services on patient satisfaction with services (Hewlett et al 2005; Hill et al 1997 Risdale et al 2000; Ryan 2006; Warren 1998). These increased levels of satisfaction were associated with the consultation style of nurses, who had more time than the medical staff to discuss psychosocial issues, provide information and advice, and provide referrals to other therapy and social care services. Hill et al (1994) and Ryan (2006) provide level 1 evidence not only of the safety of nurse-led clinics in rheumatology but also of their effectiveness in helping people to manage distressing physical symptoms such as pain and stiffness. In all of these studies the intervention nurses contribution relied on working with physicians and other nurses.

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2.4.2 Primary care settings

The majority of the community-based service delivery models in the five tracer conditions were either based in or connected to general medical practices. The nurses were invariably practice nurses or 'specialist' nurses.

The first group of individual primary care based studies looked at clinics run by 'specialist nurses' (Kernick et al 2002, Pilotto et al 2004, Ridsdale et al 1997, 1999a and McDonald et al 2000). The outcomes of these studies reflected how the individual nurse specialist role was defined or level of expertise required.

The contribution of practice nurses to chronic disease management focused on asthma care and was discussed in two clinical audit reports from the UK(Neville et al 1996, Hoskins and Neville 1999). Findings suggested that practice nurses with appropriate training had improved both the process and outcomes of care; that is, a reduction in visits to A&E departments and in the number of acute hospital admissions. A small-scale, before-and-after evaluation of a nurse-led clinic (Dickinson et al 1997& 1998) provided level 2 evidence of the reduction in the number of people identified as having high morbidity asthma in one general practice. A RCT of nurses undertaking routine reviews by telephone (Pinnock et al 2003, Pinnock et al 2005) suggested that this was a cost neutral method of improving access to care and review of symptoms.

It was notable how few studies were identified that focused on the current work of practice nurses and district nurses in supporting people with LTCs. It is increasingly difficult for researchers to design RCTs to test well-established interventions such as asthma clinics in primary care, whose clinical effectiveness might never be proved conclusively (Ram et al 2002).

2.4.3 Nurse-led care delivery: cross-boundary models

There were fifteen studies where the nursing contribution to the care of people with long term conditions involved working across traditional boundaries of care and service provision. This literature largely focused on nurse-led services focused on the interface between primary and secondary/tertiary care services, and involved specialist nurses working in liaison or outreach roles. Although one systematic review (Ram et al 2003) compared specialist nursing input for patients with COPD at home with in patient care Only one paper(Watson et al 2003) focused specifically on a multi-disciplinary team, led by a specialist nurse, which was established to promote better liaison between health and social care services for people with COPD. Three evaluations focused on specialist nurses providing a liaison service between primary and secondary care (Griffiths et al 2004,Jarman et al 2002,Mills et al 1999a,1999b) and an interview based study that investigated the views of specialist nurses, practice nurses and general practitioners about the factors which enabled effective liaison in asthma services.(Foster et al 2005).

Other papers reviewed in this category of cross boundary working included research that focused on specialist nurses providing education and symptom

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specific care in the home. These included nurses providing psycho educational interventions to improve the effects of living with severe asthma (Smith et al 2005), a Cochrane review of outreach nursing services (Smith et al 2001)and three small scale evaluations of new nurse-led services, two in England and one in New Zealand(Pilling et al 2003,Ward et al 2005,Poole et al 2001). The latter papers did not provide high level evidence of effectiveness, but provided some insight into nursing roles and responsibilities, and their impact on the process of care. The conclusion of the Cochrane review (Smith et al 2001) was that outreach programmes appeared to be resource intensive with limited measurable benefit in terms of health-related quality of life or mortality. The authors identified the need for longer-term studies that used appropriate validated instruments to measure health status and the quality of life of patients and carers.

Hospital at home is a generic term, referring to a package of home based nursing and rehabilitation services. Evidence included in this example of cross boundary working included a systematic review of hospital at home services for people with chronic obstructive pulmonary disease (Ram et al 2003) and 5 UK-based trials (Gravil et al 1998, Cotton et al 2000, Davies et al 2000, Shepperd et al 1998a, 1998b, Skwarska et al 2000).The aims of these schemes were to avoid emergency admissions or to reduce length of stay. Evidence suggests that for highly-selected patients these services were as safe as the inpatient alternative. The nurses working in these services were taking on considerable responsibility for assessment and treatment, in liaison with consultants and GPs. The implementation of hospital at home services depends on intensive support from district nursing and social care services, but this was not taken into account in any economic assessments in the above trials.

In summary, the evidence base of the contribution of nursing by the location of care was small and difficult to interpret. Research reviewed reflected the gradual trend within the NHS for nurses to assume greater responsibilities within clinical teams in all sectors and locations and the organic growth of such services in direct response to service gaps and deficiencies, reductions in doctors' working hours and the need to improve patients' access to care. Developments in the scope of nurse practice and a blurring of professional boundaries have allowed the sharing of roles and responsibilities in the multi-disciplinary team. There were studies that demonstrated that experienced clinical nurse specialists could provide a service that was as safe as, and in some ways more acceptable than, their consultant colleagues. In primary care settings there were wide variations in the levels of responsibility undertaken by practice nurses. Positive findings on the contribution of nursing to chronic disease management by location of care are ameliorated by the intrinsic heterogeneity of the roles assumed the scope of the nursing service provided and the interdependence with other services, most notably medicine.

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2.5 Research into nurse case management

The studies considered in this section are predominantly from the USA, and focus on nurse case management as one element of managed care. Case management in the US developed in acute settings first, more as a care-planning system than a care-giving one, with one nurse made responsible for overseeing the implementation of the care plan. As hospitals developed outreach services to meet the needs of more vulnerable patients, the nurse case manager role was extended to follow up a patient's progress in the community setting Cohen & Gesta (2001) and provide services that in the UK might be picked up by General Practice and linked nursing teams. In the UK the roots of case/care management are in mental health and social care provision (Challis et al 2001).

The influential Chronic Care Model, pioneered by Wagner and colleagues (Wagner et al 1996, 1998& 2001) argued that nurse case managers were essential members of the team and that nurse case management programmes had reduced risk factors in patients with established coronary heart disease, reduced re-hospitalizations in people with congestive heart failure and improved diabetes care. A challenge for reviewing research on nurse led case management however, is the lack of agreement in the literature as to what exactly this is and what it requires the nurse to do and be (Mahn & Spross 1996) suggested that in order to optimise clinical and cost outcomes the nurse case manager should be expected to have a master's degree in nursing and be accountable for managing a defined group of clinically complex or resource-intensive patients. However, these criteria have not been adopted universally. This lack of clarity on the core activities of nurse case management affects how the nursing role is identified within literature.

Eight reviews of case management that involved nurses were included. Two systematic reviews focused on primary care (Ferguson and Weinberger 1998 Veteran's Association Technology Assessment Programme2000),.two were disease specific, diabetes and congestive heart failure respectively (Norris et al 2002,Windham et al 2003), two were hospital based (Cook 1998,Kim and Soeken 2005), a selected review of care management of older people (Hutt et al 2004) and a rapid review of the comparative effectiveness of different professionals taking up the case manager role (Singh 2005a and 2005b).

In addition to the reviews, fifteen RCTS and four non-randomised controlled trials were looked at in detail. All of the trials were included in at least one of the systematic reviews described in this paper. They are considered here for the information they provide about the purposes, organisation and delivery of different models of nurse case management.

These papers were organised into five broad categories. Those that focused on in patient-based case management (Bristow and Herrick 2002, Morrison & Beckworth 1998), interventions following hospital admission (Barry 1998 Gagnon et al 1999, Egan 2002, Hodgen et al 2002, Laramee et al 2003,Pugh et al 2001, Noel and Vogel 2000, Riegel et al 2002 preventive

case management of high risk, older people (Boyd et al 1996 Hebert et al 2001, Marshall et al 1999, Newcomer et al 2004,Stuck et al 2000 Boaden et al 2005,2006, Gravelle et al 2006), Preventive case management of people with specific long-term conditions (Allen et al 2002, Aubert et al 1998, Delaronde 2002, Gabbay et al 2006 Krein et al 2004, Mullen & Kelley 2006,) preventive case management of nursing home residents(Ryan 1999,Kane et al 2001; 2002; 2003).

To complement the evidence from the five tracer conditions and research on nurse case managers and to understand the experience of both providing and receiving nursing care, papers were reviewed that could provide insight on the nurse and patient experience of chronic disease management. Many but not all of the RCTs in the review reported on patient satisfaction with care, a few qualitative studies linked to the five tracer conditions provided a different sort of evidence about the kind of nursing interventions that are valued and wanted by patients and where there might be scope for improvement. (Small and Lamb 1999,Ryan et al 2003,Ridsdale et al 1996, 2003,Monninkhof et al 2004,Jones et al 2000, Williams 2004, Fraser et al 2006). Apart from two studies (Jones et al 2000 Williams 2000), this literature demonstrated that patients valued the time and advice and emotional support nurses gave to help ameliorate the practical and emotional consequence of their condition. They also showed the wide range of expectations and needs that nurses encounter. These findings are discussed in detail in the separate report by Scott (2007) and inform the discussion and conclusions of the narrative review.

2.6 Synthesis of review findings

From an organisational and systems perspective the nursing contribution to chronic disease management within a case management approach can be summarised as falling into three separate but overlapping categories, these were:

- As a supplement to other services,
- As a substitution for other services,
- As complementary to other services.

These are each discussed in turn.

2.6.1 The nursing contribution as supplementary to other services

The nursing contribution was identified as supplementary when its purpose was to supplement existing care, compensate for service deficiencies or address gaps in patients' knowledge and understanding not provided by other services. Nursing roles to supplement other services were invariably created to address specific problems such as breaks in the continuity of service provision. This approach was evident in studies of cross boundary working in liaison roles, (Jarman et al 2002 Foster et al 2005) and across

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health and social care (Watson et al 2003) and identification of patients at risk of unplanned hospital admission (Poole et al 2001, Ward et al 2005,Skwarska et al 2000). The specific types of activities reported were regular follow up of patients by the nurse, patient education, crisis management, and co- ordination and support of social care support for people at risk or who because of their personal circumstances, low level of education health inequalities or reluctance to attend hospital had reduced understanding of their condition and access to care. The influential US based work of Kane et al (2001, 2002, 2003) is a good example of where the nurse case manager was placed in an explicitly supplementary role. The nurse practitioners were employed as case managers to supplement (and not supplant) the role of primary care physicians in managing the care of nursing home residents at risk of hospitalisation In other studies reviewed, the nursing contribution was characterised by providing ongoing disease specific education, medication review, and management for patients already receiving long term medication and treatment. The nurses in these studies were working with medical staff but extending the reach and impact of the service provided.

Across the studies which reported nurses providing a largely supplementary role, the nurses' preparation could involve a few days or an expectation that nurses would be working at Master's level. There was minimal evidence or discussion in the studies, as to whether a) their level of education and experience influenced their input and impacted on patient outcomes and b) if differently educated or experienced nurses might have achieved different outcomes. One study, where the case management approach for patients suffering with heart failure relied on telephone follow up and review, recognised that effectiveness depended on the different skills of the nurses and how they used the standardised decision support software to provide support (Riegal et al 2002). Similarly, Baird (2003) found considerable variation in the way responsibilities were shared between general practitioners and practice nurses and concluded that expanding the contribution of practice nurses to the delivery of chronic disease management, depended on improving their education and practice environment.

2.6.2 The nursing contribution as a substitute for other services.

Nurse's work was defined as a substitution for another professional when they undertook work usually done by another professional group. These studies were instituted to relieve pressure on medical workload and improve links between primary and secondary care. A recurrent preoccupation was whether nurses working in co-operation with medical teams could substitute for doctors when providing care to people with long term conditions. Invariably, the context for the nurses' work was part of a team involving doctors and focused on a specific condition with nurses working in primary care or clinic settings. Examples of the long term condition specific focus included epilepsy (Warren 1998, Ridsdale et al 2000), rheumatology (Hill et al 1994,1997,2003 Arthur and Clifford 2004), bronchiectasis (Sharples et al

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2002), asthma (Pilotto et al 2004), COPD (Pilling et al 2003), Parkinson's disease (Reynolds et al 2000), and diabetes (Gabbay et al 2006). The activities of the nurses reported in these studies included: providing patient review clinics instead of GPs, and SHOs, in depth clinical assessment of patients, symptom monitoring, initiating diagnostic tests, altering medications and clinical review, and providing ongoing advice and support. Although the nurses in these studies assumed a case manager role the distinction between disease management and case management was often blurred. One review of studies of case management of people with diabetes (Norris et al 2002) concluded case management was effective both when delivered in conjunction with disease management and also when delivered with one or more educational, reminder or support interventions. Findings suggested that nurses could provide equivalent but not less expensive care to their medical counterparts, and in some instances their patients had improved understanding and knowledge of their condition. Patients valued the availability, accessibility, and acceptability of the follow-up services provided in all clinics that involved nurses, but there is a suggestion that clinics which combined medical and nursing skills (as described by Hill et al 1994 & 1997) were more beneficial and cost-effective. These findings hints at the possible benefits of a more collaborative approach where the different professional groups have complementary skills and are providing linked but separate care.

2.6.3 The nursing contribution as complementary to other services

Complementary nursing work was defined as the work that nurses undertake because the patient requires nursing care (and not medical care or supplementary care). Papers that considered the impact of the nursing contribution as a discrete therapy or intervention that could be offered alongside other services available to the person with a long term condition were under represented (Griffiths et al 2004). Of the studies reviewed the focus was overwhelmingly on the nurses ability to absorb or substitute for the work of others (i.e. doctors) or compensate/supplement for the deficiencies of existing services, nevertheless, in some, there was a component of the nursing work that could be identified as a 'complementary.' Scott in the original review concluded that the concentration on innovation in the organisation of nursing has overlooked the evolutionary way that nurses in case management roles have developed and extended their practice to improve the processes and outcomes of "usual care". This was a significant gap in the literature. There were no papers for example on district nurses or home care nurses.

Figure 2 illustrates how organisational and system influences shape and refine the nursing contribution to chronic disease management.

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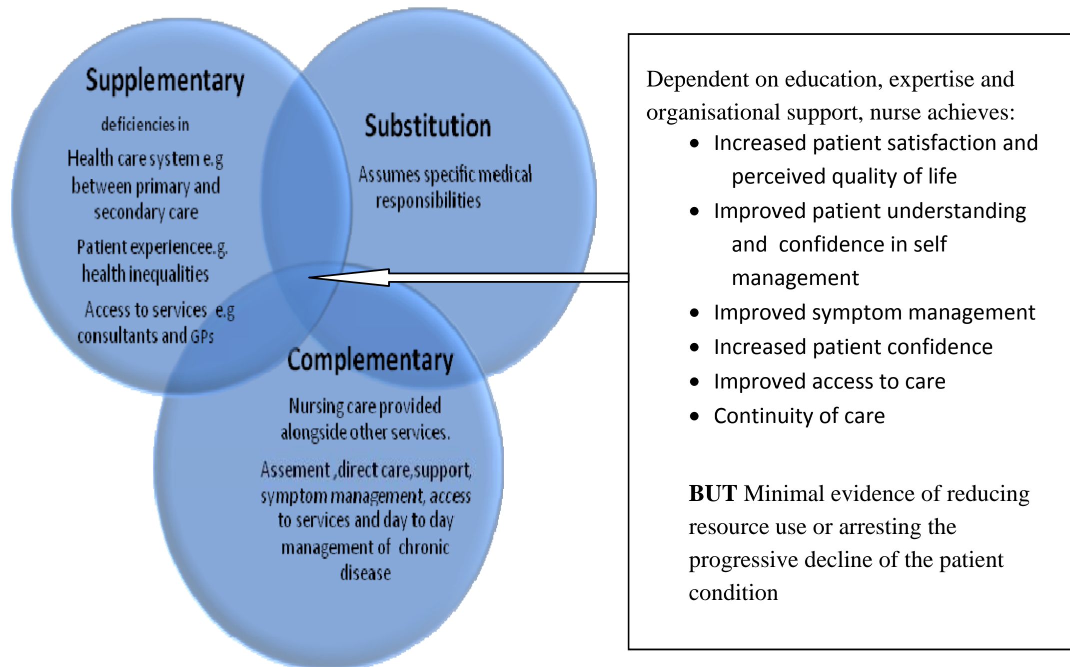
Figure 2. Diagram of organisational and system influences on the nursing contribution to chronic disease management



2.7 Discussion

The review set out to investigate the types and impact of the contribution of nurses as case managers in different models of chronic disease management. It specifically asked what type of service delivery models do nurses contribute to, what is the evidence of their impact and cost and finally what is the evidence that different types of nurses achieve different outcomes for their patients and the organisations that they work within? Despite the diverse and wide ranging nature of the evidence reviewed there were recurrent and persistent themes. We asked: 'Which sort of nurse-led service, delivered by whom, is likely to be most effective for which client groups and at what cost. There were very few studies that compared the effectiveness of different nurses in terms of different educational preparation and/or professional background when delivering the same service. There was little detailed information about the costs of the nurse-led services.

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The review identified that for those working in disease management, the key to their appointment seemed to be the specialist clinical knowledge and expertise they had acquired over time spent working in a specialised area, such as rheumatology or epilepsy. Skills in physical examination and medication management were acquired under the tutelage of medical colleagues. There was no consensus in the literature about the level of education and training needed to be effective as case managers or supporting people with specific long term conditions. The review found almost no evidence of studies that compared the effectiveness of nurses with different levels of expertise and training.

The discussion of nurses' contribution to long term conditions has a particular focus on their impact on avoiding unplanned use of hospital resources. This is most noticeable in the US nurse case management literature and in attempts to introduce US style approaches to case management. Here the evidence has been generally equivocal, and where it is difficult to know what is actually being evaluated – the effectiveness of a whole managed care programme, or the nursing component within it. There was minimal micro level evaluation of nurse-patient interactions, or interactions between nurses and their immediate reference group

There is little conclusive evidence that nurse case managers (Advanced Practice Nurses or community matrons) have been able to reduce emergency admissions or shorten the length of hospital stay. The only positive findings were in a small-scale trial from the US, where the case manager had a very small caseload and where 'usual' primary care services were reported to be weak (Boyd et al 1996) and in the Evercare study where Advanced Practice Nurses orchestrated intensive nursing care in nursing homes for people who were at high risk of hospital admission (Kane et al 2003). Various suggestions are made as to the generally inconclusive results of trials of the effectiveness of case management in the reduction of hospital admissions. These tend to focus on deficiencies in the overall organisation and delivery of healthcare, rather than on the characteristics and experience of the nurse case managers (with the notable exception of the study by Stuck et al 2000).

There is evidence that patients and their families value the individual attention and support that nurse case managers can provide to people at high risk of admission (or readmission) to hospital. What is not so apparent is that case managers will always have the personal and organisational authority needed to influence the work of a wide range of staff in other provider agencies. We found, for example, that there was little evidence of nurses being given (or taking) responsibility for the direct purchasing of health and social care services. One reason for the disappointing outcomes of case management trials is that nurse case managers alone cannot compensate for over-fragmented health and social care services.

There was limited evidence in the narrative review of nursing effectiveness when outcomes were defined as reducing hospital admissions, length of hospital services and providing individualised patient care to vulnerable patients. However without an understanding of what nurses achieve when

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not substituting for others, or supplementing for deficiencies in the service organisation, it is very difficult to distil from the evidence the ways in which the nurses' contribution shapes the patient experience and their outcomes. The review showed (Fig 2) that there are areas of work that all nurses undertake for people with long term conditions regardless of the organising context (for example education, support, continuity of care).

Some papers in the review written by nurses, or exploring their experiences in new roles, provide an insight into the supporting and inhibiting factors in undertaking that work , for example, the papers by Mills 1999 a &, b, 2002, Blaha, C et al 2000. Supportive factors reported included being set achievable targets, working with supportive teams, the perception of meeting identified needs, and having confidence in one's skills. Although these papers do not provide conclusive evidence of a causal link between context and outcome, the information they provide is in line with the findings of recent research into the relationship between supportive organisational culture and good professional practice (e.g. Rycroft Malone et al 2002).

For the purposes of the study and to inform the case study phase and subsequent analysis we returned to the three questions about the nursing contribution to the care of people with long term conditions

What kind of nurse?

For the majority of the studies reviewed, nurse case management roles were created or developed to address the shortcomings of certain services and to extend the reach of certain (medical) services. There was very little evidence to suggest that the nursing contribution was unique or that to achieve their role a specific level of education or experience was required. How the nurse worked was a negotiated act between patient/GP/consultant, subject to change and constant modification even within the timescale of individual studies. There was evidence of nurses as part of their substitution and supplementary roles, fulfilling particular activities such as acting as an intermediary, providing patient support, health education, navigating the different systems of care and technical expertise. It was not however possible to discern which of these nursing activities were particularly effective and what level of education, experience and training the nurse might require to fulfil them The absence of evidence of nurses acting as case managers as part of their everyday work with patients with long term conditions, meant it was difficult to know if what was being described was nursing in particular contexts or something different that could be reasonably described as nurse led case management. Furthermore, the minimal research (of low quality) that compared the effectiveness of different types of nurses providing care to similar groups of patients meant it was not possible to say what kind of nurse was required to provide particular types of case management activity.

There were few studies that acknowledged the heterogeneity of nursing and considered different types of nursing provision and approaches and asked if different grades of nurses (and by implication level of education and

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experience) achieved different outcomes for people with long term conditions. The literature demonstrated the wide range of work roles with different supporting mechanisms in which nurses held case management type responsibilities for patients with long term conditions. These work roles ranged from specialist nurses (with titles such as clinical nurse specialists, nurse practitioners and advanced practice nurses), who were working with high levels of autonomy and responsibility to practice nurses working to agreed clinical protocols within general practice settings.

What kind of setting?

This review focused on nursing care provided to people with long term conditions, with a particular emphasis on research where the nurse was based in primary care and had adopted a recognisable case/care management approach. The inclusion of studies of nursing management of patients with long term conditions in a range of settings; the patient's home, outpatient clinic or in hospital settings (Egan et al 2002) enabled us to consider what was shaped by organisational context and particular attributes of the nursing role (e.g. level of education and professional autonomy and authority) and what was central to the nursing contribution irrespective of location. The review has reinforced how context dependent and reactive the nursing contribution is within chronic disease management. In primary care settings, Drennan et al (2005) have suggested that the key knowledge and support required by nurse case managers (community matrons) is 'often invisible' to professionals and managers who have never worked in primary care before. The components of this include the patient-led nature of decisions about care, the comparatively small part of the nursing contribution to overall care, the fragmented and complex systems and infrastructures, and the requirement to make quick decisions in isolation from other colleagues. Of the studies, reviewed how the realities of working in primary care settings affected the nursing contribution and ultimately the outcomes were not discussed and only one (Gagnon et al 1999) discussed how this may have directly influenced decision making and patient outcomes.

What kind of outcomes?

Outcomes can be considered from different perspectives: the patient and carer, the organisation and the professionals. From each perspective outcomes can be considered in a range of domains: e.g. effectiveness, acceptability, efficiency, appropriateness, equity, accessibility (Maxwell 1992). For example in some studies organisational outcomes were defined as reducing unplanned hospital admission and improving patient adherence to treatment regimes. Some studies hint at how uneconomic certain posts are when the focus is on a particular disease or problem (Levy et al 2000) and increased service and resource use that the involvement of nurse case managers can generate will not necessarily achieve an equivalent

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improvement in patient health and function (Temmink 2001). We found little detailed information about the costs of the nurse-led services. Hutt et al (2004) in their review concluded it was impossible to separate out the individual components of the case management approach and their impact on patient health and use (both appropriate and inappropriate) of resources. Furthermore, when nursing roles were created to supplement care and address specific problems such as breaks in the continuity of service provision, or patient needs whether they had achieved this for the patient was explored but there was minimal discussion in the research of how their work affected the work of others and wider service delivery. Nevertheless, the review indicated that there is something intrinsic to the nursing contribution that patients with long term conditions recognise and appreciate. Some authors attributed this to nurses being more skilled at communication and having more time to give to the patient. It was not possible to know if the reason for their satisfaction was because of the organisation and focus (i.e. case management) of their work or finding that nurses achieve high levels of patient satisfaction

Limitations

The research literature has a number of limitations in terms of the evidence it provides. These are:

- The day-to-day contribution of nurses who have traditionally played a major part in the care of people with long-term conditions, such as district nurses and - more recently - practice nurses does not feature much in the research literature, which instead concentrates on innovative practices and new systems. Thus nursing interventions, which arguably still represent much the most important contribution of nurses to the management of long-term conditions, remain relatively under-researched.
- The available research, by concentrating on evaluations of innovations in the organisation of nursing, appears to downplay the contribution of nurses who have developed and extended their practice in an evolutionary way, so gradually improving the processes and outcomes of 'usual' care.
- This bias towards innovative organisational interventions is compounded by the relatively small scale and scope of many of the studies under review, which address local changes in service by way of (often poorly-designed) randomised controlled trials.
- People with long-term conditions, their families and carers seem not to be involved in the design of research projects, although this is one potentially valuable way of developing meaningful and appropriate patient-reported outcomes.
- Much of the research is grounded in conceptualisations of the management of long term conditions that draw on medical, financial, and administrative models, rather than social and psychological models. Reliance on measurements of fiscal and clinical outcomes often precludes the use of normative approaches to evaluation which takes account of structure and process (such as the comprehensiveness of, and ease of access to, health and social care services). Such an approach would give a higher profile to the nursing contribution to service organisation and delivery.

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- From the nursing perspective, there is another important limitation: the paucity of studies which relate their detailed empirical results to wider conceptualisations of nursing roles, this is not simply a loss in terms of potential contributions to theories of nursing practice; it also means that the overall context in which nurses contribute to the management of chronic diseases will continue to be poorly articulated and incompletely understood.
- There is scope for more research which focuses on a level beneath the local health economy, and investigated the complex but crucial inter-dependences between different professional groups in the management of long-term conditions, as well as at the micro-level of interactions between nurses and patients and families. Organisational structures and distinctive management cultures are now considered to influence standards of professional practice, by promoting good cross-boundary working and by creating an environment in which clinical practitioners can deliver patient-centred care. Investigations at this level require approaches that generate 'thick' descriptions of professional practice and systems of management. Case studies and focused ethnographies (which may be completed in less time than using traditional ethnographic methods) may not produce generalisable conclusions, but neither can poorly-designed trials, but may produce important insights that can inform policy and practice.

2.8 Conclusions

There is a growing literature on the disjuncture between the idealised representation of nurses' work and the evidence that supports its claims for a uniquely caring role. The findings of this review fit with an ongoing discussion about how nursing work is continuously being shaped by managerial and professional (medicine and nursing) agendas. (Traynor 1999, Dingwall and Allen 2001, Allen 2004, Maben et al 2007,) For community nursing in particular, workforce redesign, the creation and reorganisation of roles to absorb tasks and responsibilities from GPs and to "solve" service problems such as high levels of unplanned hospital admissions and gaps in service provision, has defined the nurses' work (Kelly and Symonds 2003, Aranda and Jones 2008). Bonsall and Cheater (2008) in their review of the impact of advanced primary care nursing roles confirm the findings and conclusions of this review. This would suggest that the findings are less about the nursing contribution to chronic disease management and more about how nurses are used by primary care organisations as "solutions" to workforce shortages and deficiencies in service.

The policy review in chapter 3 identifies a range of advocated activities by nurses (table 7) for nurses to fulfil when caring for people with long term conditions. Using the typology above it was evident that many of these advocated activities were grouped mainly in areas to substitute for medicine or to supplement deficiencies in the services.

Scott in the original review that informed this chapter argued that there was a paucity of studies which related detailed empirical results of nurses' activities in services for people with LTC to wider conceptualisations of

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nursing roles. The consequence is that the overall context in which nurses contribute to the management of chronic diseases will continue to be poorly articulated and incompletely understood. There is scope for more research that investigates the complex but crucial inter-dependences between different professional groups, the micro-level of interactions between nurses and patients and families and compares that when delivered by different types of nurses. The case study phase of the study aimed to address this need and provide an in depth understanding of how different models of case management and types of nursing shape the patient experience, use of resources and long term outcomes.

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3 The policy context and survey of nurse case management in England & Wales

This chapter addresses the study objectives 1, 2, and 3 (chapter 1.5):

1. Describe and classify the roles of nurse case managers in models of chronic disease management
2. Identify the drivers that have stimulated the development of models of chronic disease management that involve nurses as case managers
3. Describe the range and type of nurse case management models and the ways that they involve service users and carers.

It identifies the policies that have influenced explicit roles for nurses in chronic disease management and the extent to which these have been implemented at local level. This was undertaken at the macro level by a policy analysis and at the meso level by a survey of policy implementation. These will be examined in turn in this chapter.

3.1 Policy analysis

3.1.1 Background

It is estimated that over 17 million adults are living with a chronic or long term illness in the UK and that nearly 8.8 million people have conditions that severely limit their day to day ability to lead independent lives (Department of Health [DH] 2004a). The commonest of these conditions are: arthritis and rheumatism, cardiovascular and respiratory diseases (DH 2004a). The presence of one or more of these conditions rises with age (National Statistics Office 2002) and lower socio-economic circumstances (Craig and Mindel 2007). Eighty per cent of primary care consultations and two thirds of emergency hospital admissions in the UK are reported to be related to chronic illnesses (DH 2002a). As a consequence UK government health departments have focused on improving chronic disease management as a way of improving patient care and reducing costs (The Scottish Executive 2003, DH2004c, and The Welsh Assembly 2005). In all countries of the UK, the overarching frameworks draw on Wagner's model (Wagner 1996). This stratifies populations and advocates prevention and enhanced self-care for the majority and improved case management for the minority with multiple complex conditions.

3.1.2 Method

The theoretical framing for this policy analysis (Harrison 2002) has drawn on Kingdon's concepts of policy agendas and solutions (Kingdon 1984). This policy review has been undertaken by documentary analysis (Mays 1997). It identifies which policies identify nurses as "solutions" and specifically for

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which identified problems in the population and through which service response. The documents selected for analysis were:

- Guidance or policy statements related to the strategic plans for the health services, chronic diseases, long term conditions, health, and social care for older people, and nurses.
- Published between January 2000-December 2007
- Produced by Government Departments (and their service development bodies e.g. Care Services Improvement Partnership (CSIP)) in England and Wales, by policy influential arms-length government agencies such as the Audit Commission, and by policy influential service user representative organisations such as the Long Term Conditions Alliance.

In total 111 documents (see appendix 2) were identified and examined. Each document was examined using the word search facilities in PDF documents. The words 'nurse', 'nurses' and 'matrons' were sought. Each use of these terms, with the role advocated for nurses, was then mapped onto grids, against the policy streams identified in the bullet point 1 above. In addition a 'problem' list was devised derived from the policy documents and framed according to Maxwell's (1992) dimensions of quality in health care, access, appropriateness, equity, efficiency, and effectiveness. Case examples of nurses in roles related to long term conditions have been included as well as specific statements advocating roles for nurses. The reason for this is that central government made it explicit that while the centre sets the general objectives for health provision, it should be local decision making that establishes the detail of implementation (DH 2000a, DH 2002, DH 2004c). References in the policies including nurses in workforce planning numbers and in planning for education and training needs for health professionals have not been included in this analysis as these were numerous but did not specify activities or roles for nurses.

3.1.3 Results

More documents were identified related to services in England than in Wales, although it should be noted that guidance from organisations such as the National Institute for Clinical Excellence apply to both. Many documents in common do not refer to any specific occupational group but rather discuss the roles for *health professionals* or the *health care team*. Of the 111 documents examined, 35 English and seven Welsh referred to specific roles for nurses.

The types of activities advocated for nurses and in response to which type of problem are listed in Table 5 for English policies and Table 6 for Welsh policies. Table 7 provides the detailed analysis from policy in England and Table 8 from the analysis of Welsh policies.

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Table 5. Activities advocated for nurses in relation to patients with long term conditions by policies in England

Activity advocated for nurse/s	Types of problems that the advocated role addresses
1. To be a member of a MDT providing services to people with LTC	Difficulties in access to information & services. Inefficiencies and ineffectiveness of uni-disciplinary activity to people with LTC
2.To be a contact point /navigation and signposting to others	Meeting access targets in primary care. Difficulties in access to information & services. Inefficient provision/delivery/use of service (includes issues of cost to service users and to public funds)
3. Identifying Individuals with problems that can be ameliorated	Late or inadequate detection Inequity of provision
4. Case or care managers	Difficulties in access to information & services. Inefficiencies, inequities and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC
5. Assessment of problems and planning	Inequity of access to publicly funded services Inefficient provision/delivery /use of service
6. Prescribing and providing treatment	Inefficient provision/delivery /use of service (includes issues of cost to service users and to public funds).
7. Monitoring and review of patients with LTCs	Difficulties in access. Inefficiencies, inequities and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC
8. Providing continuity in care processes, smoothing and speeding transitions between home and hospital	Inefficiencies, inequities and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC
9. Providing alternative care to acute hospitals (in-patient and outpatient)	Inefficiencies, and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC
10. Providing education, information and support on conditions(s), treatments, self care to patients and carers	Ineffectiveness of current service delivery
11. Providing generalist palliative care	Difficulties in access to services
12. Assessment for registered nursing needs in care homes	Inequity of access to public funding
13. Educating other professionals about evidence based care for LTCs	Inappropriate and ineffective delivery of service

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Table 6. Activities advocated for nurses in relation to patients with chronic diseases by policies in Wales

Activity advocated for nurse/s to provide	Type of problem identified for advocated nurses role to respond to
1. To be a member of a MDTs providing services to people with chronic diseases	Inefficiencies and ineffectiveness of uni-disciplinary activity to people with chronic diseases
2. Identifying Individuals with problems that can be ameliorated	Inefficient provision/delivery /use of service (includes issues of cost to service users and to public funds)
3. Assessment of problems and planning	Inefficient provision/delivery /use of service
4. Monitoring and review of patients with chronic conditions	Inefficient provision/delivery /use of service
5. Providing continuity in care processes, smoothing and speeding transitions between home and hospital	Inefficient provision/delivery /use of service
6. Providing. education, information and support on conditions(s), treatments, self care to patients and carers	Ineffectiveness of current service delivery
7. Educating other professionals about evidence based care in long term conditions	Ineffective delivery of service

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Table 7. Analysis of English Policy Documents

Notes: References have not been included to nurses in workforce planning or in education and training needs for health professionals. All policy documents are referred to in the text by number (e.g. doc 14) as listed Appendix 3

English policy: activity advocated for nurse/s to provide	Types of problems for which nurses' activities advocated '	Nurses' activities cited in system change policies e.g. : National Service Frameworks	Nurses' activities cited in policies about : Long Term Conditions	Nurses' activities cited in policies for older people	Nurses' activities cited in policies to do with overarching Health and Social Care Strategic Plans	Nurses' activities cited in policies to do with Nursing
1. To be a member of a MDT providing services to people with LTC	Difficulties in access to information & services. Inefficiencies and ineffectiveness of uni-disciplinary activity to people with LTC	Nurses to be members of intermediate care teams (doc 23). Nurse specialist to be member of MDTS in stroke, mental health care of older people, falls teams (doc 23) and given as case examples (doc 41)	Nurses to be members of health care teams (doc 49).	Case examples of nurses as member of integrated health and social care team independent living team (doc 2)	Nurses to be members of intermediate care teams (doc 14), general practice teams managing LTC (doc 43), polyclinic team managing LTC (doc 54)	Case example of nurse in community stroke team (doc 32)
2.To be a contact point /navigation and signposting to others	Meeting access targets in primary care. Difficulties in access to information & services. Inefficient provision/delivery /use of service (includes issues of cost to service users and to public funds)		Nurse is named as contact of the LTC condition specific team (doc. 49) Case examples of nurse in specialist rheumatology MDT to staff telephone line, to book review appointments and give immediate contact/advice(doc 48,62), as contact point to streamline case management (doc 70) District nurses amongst others to pilot information prescriptions (doc)		Providing first contact /triage services by phone ,in walk –in centres, in A & E in general practices primary care and first contact in NHS Direct nurses (doc14,38,52) District nurses amongst others to pilot information prescriptions (doc 52)	Case examples of nurse specialists in COPD being contacts for MDTs (doc 37)
3. Identifying Individuals with problems that can be ameliorated	Late or inadequate detection. Inequity of provision	Hospital nurses to detect incontinence and ensure treatment is provided (doc 23), Nurses one of many who may detect abuse (doc 41)	Pilots using nurses to case find people with multiple needs currently poorly addressed (doc 43) ,	Case examples of nurses as case finding of older people with LTC (doc 2)	GP and nurse screening for LTC (doc 14) Case studies of nurses screening and case finding(doc 53)	Case studies initiating investigations(doc 37) Community matron case finding role (doc 44)

English policy: activity advocated for nurse/s to provide	Types of problems for which nurses' activities advocated '	Nurses' activities cited in system change policies e.g. : National Service Frameworks	Nurses' activities cited in policies about : Long Term Conditions	Nurses' activities cited in policies for older people	Nurses' activities cited in policies to do with overarching Health and Social Care Strategic Plans	Nurses' activities cited in policies to do with Nursing
4.Case or care managers	Difficulties in access to information & services Inefficiencies , inequities and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC	Case example of specialist nurse working as outreach from hospital team (doc 47)	Nurses as case managers of those with high clinical need, other professionals also case managers (doc 40, 45). Nurses as case managers for people with multiple complex needs to be known as community matrons (doc 45). Case examples of nurses as case managers in primary care (doc 45) , in specialist MDTs (63)	Case example of nurses as one of a MDT team of case/care managers (doc 2)	Nurses named as the likely group of specialist clinicians to be case managers to help improve approaches to chronic disease management (doc 43). The number of community matrons is to be monitored and they are expected to deliver on the national performance targets of reducing unplanned admission of people aged over 75 (doc 52, 61)	The role (doc 8,44) competencies and education required for nurses acting as case managers and community matrons are described (doc 56,98)
5. Assessment of problems and planning	Inequity of access to publicly funded services Inefficient provision/delivery /use of service	Nurses as one of many professionals to undertake single assessment process (doc 24,41) and annual medication reviews (24, 41).				Including ordering diagnostic investigations, making direct referrals (doc 32, 44). Community matrons undertake high level assessments (doc 44) Case studies undertaking assessments of people with LTC in first contact and by community matrons (doc 37,44)
6. Prescribing and providing treatment	Inefficient provision/delivery /use of service (includes issues of cost to service users and to public funds)	Specialist nurses as part of specialist MDT initiating treatments e.g. CHD and CVA –thrombolysis , diabetes – insulin (doc 16,24,) GP initiates treatment including District Nurse if required (doc 36)	Case example of a rheumatology nurse practitioner, with others developing guidelines for patient self administered methotrexate (doc 63)		Extending nurse prescribing (doc 14). Case examples of specialist nurses providing anti-coagulation service, Practitioners with specialist interests and specialist dermatology nurses providing treatments (doc 45).	Community matrons prescribe and provide clinical care (doc 44). Case examples of nurses prescribing and starting treatments in first contact services (doc, 32,37). Case example of anti-coagulation treatment clinic by nurses (doc 32)

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English policy: activity advocated for nurse/s to provide	Types of problems for which nurses' activities advocated '	Nurses' activities cited in system change policies e.g. : National Service Frameworks	Nurses' activities cited in policies about : Long Term Conditions	Nurses' activities cited in policies for older people	Nurses' activities cited in policies to do with overarching Health and Social Care Strategic Plans	Nurses' activities cited in policies to do with Nursing
7.Monitoring and review of patients with LTCs	Difficulties in access. Inefficiencies, inequities and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC	Specialist nurses in heart failure and diabetes to run their own clinics outside of hospitals (doc 16, 35) Nurses as well as GPS and pharmacists to offer annual medication reviews to older people (doc 24,41)	Case examples of nurse specialist in respiratory conditions (doc 63), CHD (doc 45). Case examples of nurses staffing the telemonitoring service for LTC (doc 45)		Specialist nurses involved in monitoring and review of people with LTC (doc 43) . Case example nurse at call centre for people with LTC (doc 69)	Community matrons undertake this role with people with multiple LTCs (doc 44) Case example of nurse undertaking monitoring as part of heart failure team (doc 44)
8. Providing continuity in care processes, smoothing and speeding transitions between home and hospital	Inefficiencies, inequities and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC	A specialist nurse to co-ordinate information and care between specialist team and hospital ward teams and primary care (doc 35) A named nurse for co-ordination of nursing care and transition between hospital and community (doc 23)	Case studies of specialist Parkinson's nurse and MS nurses (doc 71)	Case example of a 'tracker' nurse to co-ordinate integrated health and social care (doc 2)	Case examples of specialist nurses enabling shorter stays in acute hospitals (doc 54)	Case example nurse as telephone navigator to GPs who are trying to refer/admit to hospital (doc 37)
9. Providing alternative care to in-patient/ acute hospitals (in patient and outpatient)	Inefficiencies, and inappropriateness of provision /delivery /use of service (includes issues of cost consequences to service users and to public funds) for people with LTC	A specialist nurse to co-ordinate follow up post inpatient episode to reduce outpatient appointments and non-attendance at outpatients (doc 35)			Nurses as members of intermediate care teams e.g. hospital at home, rapid response etc teams (doc 14) Case example of nurse led community hospitals (doc 53) Post discharge follow up of simple things by nurse or community worker /telephone (doc 53)	Community matrons provide monitoring and clinical care to prevent hospital admission (doc 44)
10. Providing. education, information and support on conditions(s), treatments, self care to patients and carers	Ineffectiveness of current service delivery	To be delivered by a specialist nurse for people with CHD (doc 16)	Case examples of delivery by specialist nurses for multiple sclerosis (doc 63, 45), Parkinson's disease and diabetes (doc 45, 55) and COPD (doc 45).			Community matrons teach, educate and provide information for the person and their family/carers(doc 44)

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English policy: activity advocated for nurse/s to provide	Types of problems for which nurses' activities advocated '	Nurses' activities cited in system change policies e.g. : National Service Frameworks	Nurses' activities cited in policies about : Long Term Conditions	Nurses' activities cited in policies for older people	Nurses' activities cited in policies to do with overarching Health and Social Care Strategic Plans	Nurses' activities cited in policies to do with Nursing
11. Providing generalist palliative care	Difficulties in access.	Nurses to provide generalist palliative care to people with LTC (doc 47)				
12. Assessment for registered nursing needs in care homes	Inequity of access to public funding	A suitably trained nurse to undertake the assessment of need for registered nursing care while resident in care home (doc 24) later expanded to be one amongst other professionals (69)		Assessment of need for registered nursing care while resident in care home (doc 28)		
13. Educating other professionals about evidence based care for people with long term conditions	Inappropriate and ineffective delivery of service	Nurse specialists and consultants in older people to educate staff caring for older people (doc 23)				

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Table 8. Analysis of Welsh Policy Documents

Notes. 1. References have not been included about nurses in workforce planning and in education and training needs for health professionals. 2. All policy documents are referred to in the text by number (e.g. doc 14) as they are listed Appendix 2.3. There are no specific roles advocated for nurses in policies related to older people, or roles for nurses in chronic disease management in policies related to nurses.

Welsh policy : activity advocated for nurse/s to provide	Type of problem identified for advocated nurses role to respond to	Nurses activities cited in policies to do with : National Service Frameworks	Nurses activities cited in policies to do with : chronic diseases	Nurses activities cited in policies to do with ; overarching Health and Social Care Strategy and Plans
1. To be a member of a MDT providing services to people with chronic diseases	Inefficiencies and ineffectiveness of uni-disciplinary activity to people with chronic diseases	Practice nurses, nurses with specialist interest in respiratory part of MDTs (doc 108) Respiratory nurses in MDTs for pulmonary rehabilitation (doc 108) Diabetes specialist nurses in specialist MDTs (doc 103). Coronary heart disease specialist nurses to support primary care CDM (doc 100) Specialist nurses as part of cardiac MDT deciding on method of revascularisation (doc 100)	Specialist nurses one of many resources for CDM (doc 109) Specialist nurses and nurses with special interest in primary care to be one of networked team for level 3 high risk CDM (doc 109).	Nurses with specialist skills as one of team for chronic disease management (CDM) (doc 104)
2. Identifying individuals with problems that can be ameliorated	Inefficient provision/delivery /use of service (includes issues of cost to service users and to public funds)	Practice nurses as one of team identifying COPD problems (doc 108)		Case example of practice nurses identifying problems early, referring to DN for extra input and helping to avoid hospital admission via emergency routes (doc 104)
3. Assessment of problems and planning	Inefficient provision/delivery /use of service	Practice nurses as one of team working with people with COPD (doc 108)		

Welsh policy: activity advocated for nurse/s to provide	Type of problem identified for advocated nurses role to respond to	Nurses activities cited in policies to do with : National Service Frameworks	Nurses activities cited in policies to do with : chronic diseases	Nurses activities cited in policies to do with ; overarching Health and Social Care Strategy and Plans
4. Monitoring and review of patients with chronic conditions	Inefficient provision/delivery /use of service		Case example appropriately trained nurses undertaking reviews of chronic conditions (doc 109)	
5. Providing continuity in care processes, smoothing and speeding transitions between home and hospital	Inefficient provision/delivery /use of service	Specialist heat failure nurses (doc 100) and specialist diabetes nurses (doc 103) assisting in early discharges		
6. Providing. education, information and support on conditions(s), treatments, self care of patients and carers	Ineffectiveness of current service delivery	Specialist nurses for coronary heart disease to lead cardiac rehabilitation programmes and teach patients self care (doc 100)		
13. Educating other professionals about evidence based care in long term conditions	Ineffective delivery of service	Coronary heart disease specialist nurses to support primary care in CDM (doc 100)	Specialist nurses in diabetes to teach other nurses (doc 103)	

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3.1.4 The policy review: discussion

There are relatively few references to nurses specifically in documents of this period. To some extent this is a function of the documents referring to health professionals in general rather than spelling out specific roles for individual professions. In the period 2000- 2007 there is a preoccupation in both countries with increasing and retaining a skilled healthcare workforce. Nurses feature (with other named professional groups) in the workforce section of all the documents related to overall strategy, older people, and long term conditions.

The Welsh documents refer to fewer roles for nurses in services for people with chronic diseases. English policy specifies roles for nurses and gives case examples in more types of activities for nurses (13) than Wales (7). The additional activities indicated in the English policies are:

- As a contact point and navigation guide to services,
- As a case or care manager,
- As a prescriber and provider of treatment,
- As a provider of care services as an alternative to the acute hospital,
- As a provider of generalist palliative care,
- As an assessor of the need for registered nursing care while in a care home.

Many of the roles for nurses in the English policies are specifically linked to central government targets for improving time periods to access a consultation with a health professional, reducing unplanned acute hospital admissions and reducing length of stay in acute hospital for adults with long term conditions.

The Welsh review of evidence for managing chronic conditions specifically considered the question of nurses as case managers for people with chronic conditions and concluded that there was not sufficient or robust enough evidence to support the nurse case manager or community matron type model (Welsh Assembly 2006). The policies creating a new role in England called community matrons (DH 2004c, 2005b) are markedly different to the Welsh approach. The English Department of Health:

- Specified the community matron role and activities in detail (DH 2005b),
- Published its required competencies and education (NHS Modernisation Agency & Skills for Health 2005),
- Set a national target number (3,000) to be appointed by a defined date, initially April 2007 then 2008 (DH 2004c, DH 2004g),
- Monitored the numbers recruited, initially by strategic health authorities and then by PCT performance reporting to the Healthcare Commission (DH 2004f)
- Linked the introduction of this role to a Treasury Public Service Agreement target of reducing unplanned hospital admission for people aged over 75 (HM Treasury 2004).

The level of specification and political focus on the community matron role by the central Department of Health were unusual for any nursing post (or any health professional post for that matter) although there was some precedence in the creation of the modern matron role (DH 2000a).

One activity, specified only in the English documents, relates to judgements for eligibility for public funding support, and that is the assessment for registered nurse care in the care homes. This system does not exist in Wales and has been amended subsequently in England (DH 2007b).

Most references advocating an activity for nurses refer to condition specific specialist nurses e.g. diabetes specialist nurse or nurses with specific additional training e.g. community matrons. There are very few references to generalist nurses in primary care. Practice nurses feature in a number of the Welsh documents but district nurses are named only twice (in English documents).

Some of the activities advocated for nurses cluster around the nurse *substituting* for a doctor such as in assessment, prescribing and treatment. These activities are advocated in relation to problems with inefficient provision and delivery of services as well as difficulties for services users being able to access services within set time frames. Examples include specialist nurses in heart failure providing clinics for patient follow-up in the community.

Other activities advocated for nurses cluster around *supplementing for weaknesses* in the system of delivery of service in order to improve perceived problems of inefficiency, inequity, and inappropriateness. Some of these activates are directed towards services and others directly interface with the patients. Examples include specialist diabetes nurses providing information to hospital ward staff about admitted patients and assisting in discharge arrangements, community matrons providing medical monitoring, and prescribing treatment changes for patients with multiple long term conditions at home.

A few activities advocated for the nurses indicate *strengthening* provision to address ineffectiveness in current service delivery. Examples include the provision of information, education, and support on conditions and treatments by specialist nurses or community matrons.

3.1.5 The policy review: limitations

This documentary analysis has a number of limitations. As indicated earlier many documents refer to health professionals in general and not specific groups. Therefore the intention of policy makers could be for nurses to contribute to services for people with long term conditions in many more ways than specified here. The analysis covered only 7 years and other relevant documents may have been published earlier. Our intention however was to analyses the policy direction for nurses in contributing to chronic disease management provision for adults, in order to direct the later stages of the study and consider it against the implementation at the meso-

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level of health service delivery. The next section reports on the survey that investigated the implementation of policy.

3.2 The survey

This section reports on the mixed methods survey which addressed the following questions:

How had the central government policy frameworks relating to improved services for people with long term conditions influenced the development and implementation of local strategies and policies?

How had case management models been implemented and evaluated with particular regard to models involving nurses as case managers with people with long term conditions?

The full report of the survey is available separately (Drennan et al 2008). This section summarises the methodology and findings.

3.2.1 The survey method

A mixed method survey approach employed both documentary analysis (May 1998) of primary care organisations' publicly available strategies for long term conditions management and semi-structured telephone interviews with key informants (Robson 2002). The original design had been for an electronic postal survey of senior managers, however, the organisational turbulence and deletion of many senior management posts in the major re-organisation of English Primary Care Trusts of this period meant that this method of surveying was impossible at this time. A revised methodology was developed and agreed with the study commissioners. The methodology is detailed below. The study was reviewed under University Research Ethical Review procedures and was not required to have NHS research ethical review (NHS Central Office for Research Ethics Committees 2006).

Local health service strategy documents that included plans for addressing the local population with long term conditions (LTC) were sought from the internet websites of up to four PCTs in each of the eight English Government Regions, and up to four of the Welsh Local Health Boards (LHB). Thirty seven strategy documents in the public domain were retrieved that explicitly included the population with LTCs, four in each of eight English Government Regions and one from a Welsh LHB. No other was found in Welsh LHBs. Each strategy document was read and data identified against a data extraction sheet by two researchers. The data extraction sheet included questions on: the types of service models for addressing long term conditions and models of case management used in relation to long term conditions and any related service targets. Data was also noted on any supporting infrastructure such as; links with local authority social care services; patient involvement in LTC management and workforce development. References to any local evaluation reports of long term conditions management strategies were also sought.

The semi-structured interviews were designed to gain more in-depth detail on models of nurse case management, local factors influencing the models and infrastructure and evidence of impact. Participants for the semi-structured telephone interviews were recruited through two routes:

- Invitation letter and emails sent to nurse directors of PCT, LHB and acute trusts identified in the *Directory of Community Nursing* (Professional Managerial and Health Care Publications Ltd (2006),
- Invitation letters sent to members of the Royal College of Nursing (RCN) managers' forums in England via RCN professional officers.

Forty one informants were recruited from across the 10 English Strategic Health Authorities and two Welsh Local Health Boards. The types of health economies that the informants reported from were diverse: 17 served inner urban or urban populations, four served rural populations, and 20 served mixed urban and rural populations. Notes were taken during the interviews which were then transcribed and copied to the informants for verification and any amendments. The transcribed notes were analysed by two researchers independently using a template methodology (Crabtree and Miller 1992). The analysis from both elements of the study was integrated in a second level of analysis comparing and contrasting the data against the research questions.

3.3 Findings from the survey Results

3.3.1 The influence of central government policies on local strategies

The most predominant policy influence, as cited in the strategy documents, was the Treasury Public Service Agreement (PSA) target (HM Treasury 2004) for the Department of Health. Twenty six documents made specific reference to this target which stated that each PCT had to decrease emergency hospital admissions of people aged over 75 by 5% by March 2008. Only 16 documents made reference to the other element of this PSA target which stated that vulnerable people with long-term conditions, most at risk of unplanned hospital admission should have a personalised care plan (HM Treasury 2004). A minority of local strategies referred to other specific policy targets which included the introduction of community matron posts (DH 2004c), a reduction in heart disease (DH 2000b) and the rolling out of the Expert Patient Programme (DH 2001a) by 2008 (DH 2006). The informants in England confirmed that specific policy targets were driving the introduction of a range of strategies and service developments for people with long term conditions. They reported that the current impetus for the introduction of nurse case management roles came from the Strategic Health Authority (SHA). Each SHA had set targets for the number of community matron posts that individual PCTs had to employ. These in turn were linked to the PCT performance targets of reducing unplanned emergency hospital admissions in people aged over 75. Only one Welsh LHB strategy document for chronic conditions was found and this made no reference to nurses or nurse case management, the focus of this

investigation. This was congruent with the available Welsh Assembly Government documents at the time of the search (see Table 8 above). The 2 informants in Wales were aware of Welsh policy initiatives to improve chronic condition management but reported that the development of case management, and specifically nurses as case managers, was in its infancy in their areas. One informant was aware that a pilot project of nurse case management work was occurring in another LHB. The remainder of this section therefore analyses the data from the 36 strategy documents and the 39 informants from English PCTs.

3.3.2 Local implementation: commissioning processes and financing

There was little information in the strategy documents on commissioning processes, including practice based commissioning, and its influence on the implementation of LTC strategies. More common were references to inter-agency planning committees such as 'long term conditions Boards' and Steering Groups. Several PCTs were involved in partnership arrangements with Local Authority adult services and the hospital sector in order to improve the care of people with LTC. Other cross agency supporting infrastructures commonly referred to were 'care pathways' and 'the Single Assessment Process'. The need to establishing better relationships between primary and secondary care was also a common theme. Some documents referred to other strategies to be pursued: greater involvement with the voluntary sector (three PCTs); increased links with mental health services (two PCTs); chronic disease collaborative between GP practices (1 PCT) and closer working with intermediate care (1 PCT).

Few references were made to costs or funding for the LTC strategy or any new developments. Of the 36 documents examined only one identified PCT growth monies as a source of funding for implementing a new case management service. In this PCT the growth monies were to be used in PCT provider services and in general practices through locally enhanced service contracts. Two other PCTs referred to short term monies for nurse case management posts obtained from Strategic Health Authority workforce development funds. Informants confirmed that the pressures on finance locally were an important factor in shaping the introduction of case management and specifically community matrons. Some informants described business cases for new posts that were linked into the performance targets and an implication that failure to meet the targets would raise questions regarding the continuation of the service as exemplified by this quote:

"We've introduced community matrons on an invest to save basis: if they can demonstrate admission avoidance the service will pay for itself". (Informant 35 East of England).

Others described an implementation process born of pragmatism in an unfavourable economic climate:

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"It hasn't been viable for this PCT to introduce stand alone Community matrons, so the introduction of case management across the board has been a struggle. You've got to work with what you've got and we are a small PCT with a big deficit". *(Informant 3 Yorkshire and the Humber).*

One informant reported that the CM team was established in partnership with a private health care company reflecting the contemporary interest in mixed economies of provision being promoted in broader government policies for primary care in England (DH 2006).

There was little reference to patient, carer, and voluntary services involvement in LTC management. Eight documents reported that patient and public representatives were involved in the development of case management strategies, most commonly through their inclusion on the LTC steering groups.

3.3.3 Local implementation: the range of case management models

Five documents made no reference to this type of service at all, suggesting they were not going to develop this service. However all informants reported on the introduction of some form of case management service for people with long term conditions, often with timescales linked to the PSA targets and community matron targets. A few documents and informants referred to a case management model based on the English policy document, an 'NHS & Social Care model' (DH 2005a). many more made reference to other types of models based on both UK demonstration projects e.g. 'Castlefields' in the Northwest of England (DH 2005b), Unique Care (Lyons et al 2006), EPIC in Cornwall (Lyndon 2007) and also frameworks from the United States of America e.g. Evercare (United Health Europe 2005) and a 'Kaiser Permanente' model. Informants offered some very different models of LTC case management and hospital avoidance than those described in the DH policy documents. One example of this was in the South East, where an integrated primary care and treatment approach had been developed involving GPs. In this model a GP undertook case management of complex patients at risk of hospital admission with multiple conditions and nurse specialists undertook care management of those patients with a single condition e.g. diabetes.

3.3.4 Case finding

Informants implementing nurse case managers referred to the introduction of systematic case finding of people aged over 75 at risk of re-hospitalisation. The majority of PCTs were using the PARR tool (patient at risk of readmission [Kings Fund undated]) for case finding. Other tools in use included, RISC (United Health Europe undated) and MIDAS (Middlesborough PCT Undated). The informants reported a number of challenges with the use of case finding tools:

- Locating patients through their NHS numbers was a time consuming process that had raised a number of data protection and confidentiality issues,

- Limited access to IT support for running the case finding tools effectively on a regular basis,
- In practice, PARR2, the most widely used tool, was reported to pick up the same patients each month and did not always identify any new cases.

Other reported case finding strategies included identifying patients with frequent hospital admissions and/or frequent attendance at GP practices as well as being over 65 years old and having one or more LTC. Many informants reported that the community matrons also took referrals from other professionals both in the hospitals and in primary care.

3.3.5 Professional background and role of case managers

A minority of areas reported that other professionals, such as therapists, were employed in case manager posts but informants perceived these posts as developing differently from the nurse case managers:

"The PCT also employs two therapists as case managers: an occupational therapist and a physiotherapist who have been in post for 18 months to 2 years. They case manage but the role is emerging with some differences. They have a bigger focus on rehabilitation whereas the community matrons tend to see patients who are unwell and may need admission to hospital. The therapist case managers and the CMs have had some common training but they (the therapists) are not able to prescribe and do not have the same clinical skills." Informant 33, East of England

The informants reported that it was mainly nurses being employed as case managers albeit with a variety of titles e.g. community matron (CM), advanced primary nurse, older adults case managers. The expectation was that the nurse case managers would use clinical diagnostic skills and their prescribing powers. One reported barrier to the implementation of case management was the problem of recruiting suitably qualified nurses to these posts.

A variety of nurse case management roles were reported to be in use. These have been listed and categorised according to whether the nurses worked as generalists (i.e. with patients with any LTCs) or with a specific client group (see table 9 below).

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Table 9. Types of nurse case managers from key informant interviews

Types of generalist case managers:	Types of client group specific case managers:
Community matrons (stand alone posts)	Nurse specialists e.g. respiratory, CHD,
Community matron with a district nurse dual role	Condition specific community matrons. e.g. respiratory
District nurse (DN) as case managers	Nursing home case managers
Existing DN team leaders who are also case managing	Part falls prevention, part generic community matron
Generic case managers (background in a therapy, nursing or social work) who did not use advanced clinical skills	Nurse practitioners in general practice

Generalist case managers were either community matrons or district nurses, or both, although one PCT had generic case managers with a background in social work and physiotherapy as well as nursing. Client group specific case managers were nurse specialists in the main but also included some community matrons and nurse practitioners. The three most common conditions reported to being case managed by community matrons were COPD, heart disease and diabetes.

The majority of nurse specialists were reported to be PCT employed and based but some were sponsored and funded by charities e.g. British Heart Foundation and British Lung Foundation. Some nurse specialists worked as outreach from an acute hospital and consultant team. One informant described nurse case management of people with strokes to facilitate co-ordination of care in the hospital and during community rehabilitation, describing the roles as "moving the patients care forward" (Informant 26 Yorkshire and Humber). In some PCTs acute based nurse specialists were said to be moving into the community under PCT employment. Some informants noted that not all nurse specialists were case managing; especially those who were employed and based in an acute care service.

Two examples of specialist nurses and 3 examples of CMs were cited as case managing people resident in nursing homes. Five informants described specialist nurses and community matrons undertaking case management work within medical admissions (assessment) units of acute hospitals to facilitate shorter hospital stay.

In a few PCTs the model of community matron had been developed from a single post to one where the post holder supervised a team of registered nurses and assistant practitioners. The staff in these posts were reported to cover a range of monitoring work but not the comprehensive assessment or care planning.

In some PCTs the introduction of CMs was accompanied by the piloting of assistive technology including the provision of alarms for patients on appliances, access to call centres and in some cases self-assessment, in areas such as blood pressure measurements, which could be accessed by

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CMs. Some CMs were also reported to have access to diagnostics in community hospitals.

3.3.6 Case manager relationships with other services

Beyond the broad model of case management there was variation in the relationship between the nurse case managers and medical and social services colleagues as well as variation in their physical location and which patient groups comprised their caseload. This variety is presented diagrammatically (figure 3).

About a third of informants reported that case managers were based in GP practices and that there were mainly close working relationships with general practice. Overall, a spectrum of relationships was described. At one end, case managers were part of the general practice team, received regular mentoring by GPs, had access to and recorded onto the general practice computerised patient records and jointly reviewed patients for case management with GPs. At the other end of the spectrum, some case managers were reported to have little or no contact with GPs.

A variety of mechanisms were reported on CM work at the interface between primary and secondary care. For example, some hospitals were reported to have systems to notify CMs of all case managed patients who entered A & E or the medical assessment unit. In addition some CMs were reported to receive significant clinical support and mentorship from consultant geriatricians.

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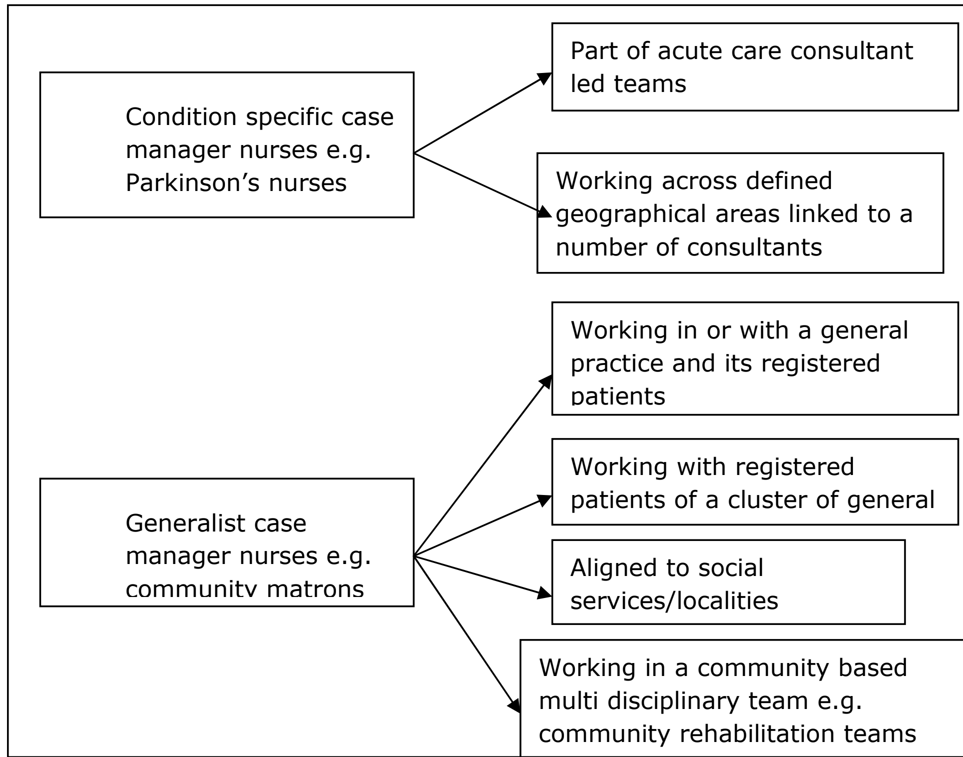
Figure 3 Diagram of the reported types of nurse case managers and their service relationships



In terms of relationships with the district nursing service, there were some CMs who were integral to the district nurse team while others stood alone. All of the informants reported that the CM service was only available on week days and mainly office or extended office hours. Most informants reported that the DN service provided cover in the CMs absence:

"Out of hours care for the case managed patients is a problem. There is the twilight DN team and the rapid response team but there is obviously a gap, so we are planning to develop an out of hours team with the same skills of assessment to case manage and pick up new patient" .Informant 21, South Central England.

A variety of arrangements for integration between health and social care services was also reported. In three PCTs the CMs were in the same teams as social services care managers. Some PCTs reported a long history of joint posts and co-location of health and social care staff, which was said to facilitate closer working relationships and integration in general:

"Health and social care have been integrated for a while in this PCT in relation to older people with complex needs. We have 8 joint case managers based in adult social care services, who have a nursing background,

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commissioning long term care placements and other care packages." Informant 22, Yorkshire and Humber

Only 1 informant identified nurse case managers as having access to a budget for additional support or services for patients. This was a budget to fund support for patients in the last weeks of life, wishing to die at home. One informant noted that CMs were able to admit patients to community hospital beds, while 2 others noted that the agreements were being made for CMs to access inpatient beds for their patients:

"From the beginning of the next financial year the CMs will be able to refer patients directly to acute or step up beds." Informant 39, London

3.3.7 Caseload size for case managers

All the community matrons were employed by the PCTs but there was a wide variation in reported numbers, from between one and 45, which could partly be attributed to the merging together of some of the PCTs in October 2006. Likewise, the number of nurse specialists within the PCTs varied; one trust employed only one specialist nurse, whereas others reported at least 3 teams of specialist nurses for different long term conditions.

Seven PCT documents specified numbers of patients in the caseloads for case managers. These varied between 50 and 80 patients (NB the NHS and Social Care Model suggested 80 complex patients on a single caseload, DH 2005a). The community matrons' caseloads were reported to range between 6 and 85 patients. Factors reported to influence this included the length of time the community matron (CM) had been in post and how many days training they were attending each week:

"Their caseload has been a bone of contention here , firstly because it has taken a while to build up as they have been involved in intensive training over the first year, but also because the suggested 50-70 patients is very difficult to achieve in terms of intensive case management. They are currently trying to build up to about 40 patients per community matron." Informant 30, London

Nurse specialists' caseloads were reported to have a more consistent number of between 20 and 40 patients to case manage. Informants reported there was little overlap between the DN and CM caseloads, and many of the CM patients were not known to the community nursing service.

3.3.8 Local implementation: consequences for other services

In 12 PCT documents reference was made explicitly of the organisational consequences for district nursing of introducing this new type of nursing service. Terms such as 'review', 'redevelop', 'modernise' and 'redesign' were used to describe changes within community nursing. In some cases this restructuring was projected positively in the documents with increased capacity, but in one PCT it was described as 'maximising scarce skills':

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"We have had a complete review of the DN service with the brief to introduce CMs, case management by DNs and increase equity in access to services but within the existing finances and staff. In reality because of financial difficulties, the DNs do not have enough staff to delegate to so they are not always case managing." Informant 19, South East England

At least 16 PCTs were reported to have altered the profile of their district nursing teams to compensate for the movement of DN team leaders into CM posts. Reported changes included more health care assistant posts, new types of posts such as assistant practitioners, and community support workers with a generic role to support health and social care across the agencies.

3.3.9 Local Implementation: reported challenges

As noted earlier, financial resources were a significant challenge in implementing a new case management model. The lack of suitably qualified staff was another difficulty, combined with a lack of suitable clinical skills training and mentorship.

An additional barrier in some areas was the reported scepticism or a lack of support regarding community matron services on the part of some GPs:

"The GPs have not been very receptive to the CM role because they couldn't see what they were doing. This resulted in some difficulties for the CMs but if the CMs demonstrated admission avoidance and the like, then they have been more willing to work with them." Informant 15, North East England

Some informants noted that negative attitudes on the part of GPs had been exacerbated by the accompanying re-organisation of district nursing services, in which established DN links to general practice were dismantled or DN staff re-allocated. Conversely, some informants identified GPs as champions of community matrons and considered that practice based commissioning might offer new opportunities to develop the service. Many GPs were reported as yet to be convinced about the benefits of community matrons for their patients and were reluctant to provide mentorship without reimbursement. Some PCTs reported developing strategies to engender GPs' trust such as seeking GP champions to work with and mentor CMs, and involving CMs in the GMS contract quality and outcome framework (QOF) data collection for the practices in return.

"We tried not to ask for GP support to the CMs on a monetary basis but sold the role as a bonus for practices which benefits GPs and their patients. The CMs do some practice nurse triage work and get support from the GPs on individual cases." Informant 21, South Central England

It should be noted that GPs were not the only group of professionals who were reported to be not supportive of new CM posts. Informants noted that in some areas medical consultants were similarly sceptical. Two informants reported that district nurses also initially viewed the posts negatively and there had been confusion over the differences in the roles.

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3.3.10 Local implementation: evaluation of case management

Information on evaluation of case management was only reported in 7 PCT documents. The following measures of evaluation were suggested in these documents: surveys of patients, routine hospital and GP data, cost benefit analysis, quality of life measures, and patient and staff satisfaction, monitoring emergency bed use / admissions avoided, National Service Framework targets and a ISIP Benefits Realisation Exercise (NHS Integrated Service Improvement Programme (ISIP) 2006) to identify improvements for patients from LTC service redesign. No document reported any evaluation that we could access. Only 1 informant identified a local formal evaluation after the first year of the introduction of community matrons. This involved comparison of patient data pre-and post the introduction of the posts. The reported main change had been an 80% reduction in GP contact by the patients during the 12 months of the CM contact. Most informants reported that data were collected as part of the ongoing service monitoring. On going monitoring at the local level was reported to be focused on the performance linked to the PSA target to reduce emergency bed days by 5% by 2008. Some PCTs were using recognised tools as part of this such as the Dudley PCT tool (undated) and Conrane Evaluation Tools (Conrane consulting 2006). This monitoring was reported to include factors such as:

- The number of referrals to case managers,
- Size of the case managers' caseload,
- Numbers of types of medication being taken,
- The number of co-morbidities of patients,
- Number of acute admissions avoided,
- Reduction in the length of hospital stay,
- Patient contact with Accident and Emergency services.

Few informants were able to share evidence of impact e.g. one informant reported from a sample of 50 patients there had been a 40% reduction in admissions on the previous year but noted this had been hard to validate. Only one informant offered some information on financial benefit to the NHS:

"An interim audit has been carried out with the finance team looking at data pre-and post CM introduction to monitor the impact financially: £25,000 was saved in the first 5 months." Informant 16, South East England

Some informants observed that it was easy to demonstrate a reduction in hospital admissions six months after the introduction of CM case management, but once patients were stable they were at less risk of admission. In addition, some stated that no record was being made of the number of patients who were downgraded from level 3 to level 2; another possible way of evaluating the impact of case management. Positive anecdotal evidence was reported from patients and carers through 'patient stories' and some small patient satisfaction surveys. Patients were reported to be satisfied:

"We have looked at patient satisfaction with a questionnaire; which has been very positive. Patients like the continuity of having one person they see and can easily contact." Informant 13, North West England

Two informants reported that 1 patient in one area and 2 patients in another had declined the service at the initial approach.

3.3.11 The survey: limitations

Each element of the survey has methodological limitations. For example, the documents studied were only those that could be found on the internet and may not be representative of all the planning documents and strategies available if we had sought hard copies directly from organisations. The methodological strategy of ensuring sampling from all Regions tried to address this sort of limitation. The second element of telephone interviews with a range of informants, also from every region of country, allowed comparison with the documentary analysis. Comparison of the evidence between the two elements showed little dissonance and therefore offers a measure of confirmation in the trustworthiness (Robson 2002) of both the approach and the range of issues revealed in relation to the research questions. The concluding discussion for this chapter considers both the policy review and the survey.

3.4 Discussion and conclusions

The policy review found only a small number of specific references to roles for nurses in LTC management. Groups such as district nurses were noticeable for their absence. Specialist nurses and nurse case managers were given very specific tasks and roles in England. The survey at the local level identified that in England this policy direction, specifically those with centrally monitored targets, had an impact on local decision making regarding the introduction of nurse case managers. In Wales central government direction was absent and it was apparent at the local level there was not the same emphasis on nurse involvement in LTC and as case managers. However, it was notable that in England, despite very specific guidance on nurse case management, local decision making resulted in a wide variety of nurse case management models and nurse involvement in admission avoidance strategies for people with long term conditions.

In pursuing the implementation of the central policy, informants described an environment of local funding difficulties, local variations in availability of skilled nurses and nurses with these types of skill competencies, local resistance to the central policy from medical and nursing groups. They also described local environments where over a number of years there had been active pursuit of improving primary health care and social care delivery to adults with complex, long term conditions. In these contexts there were already service developments in which similar (to the central policy) but not identical nurse case management roles featured. As a consequence, the informants give the impression of local pragmatic solutions being found to advance the overarching intent of the central policies while addressing local

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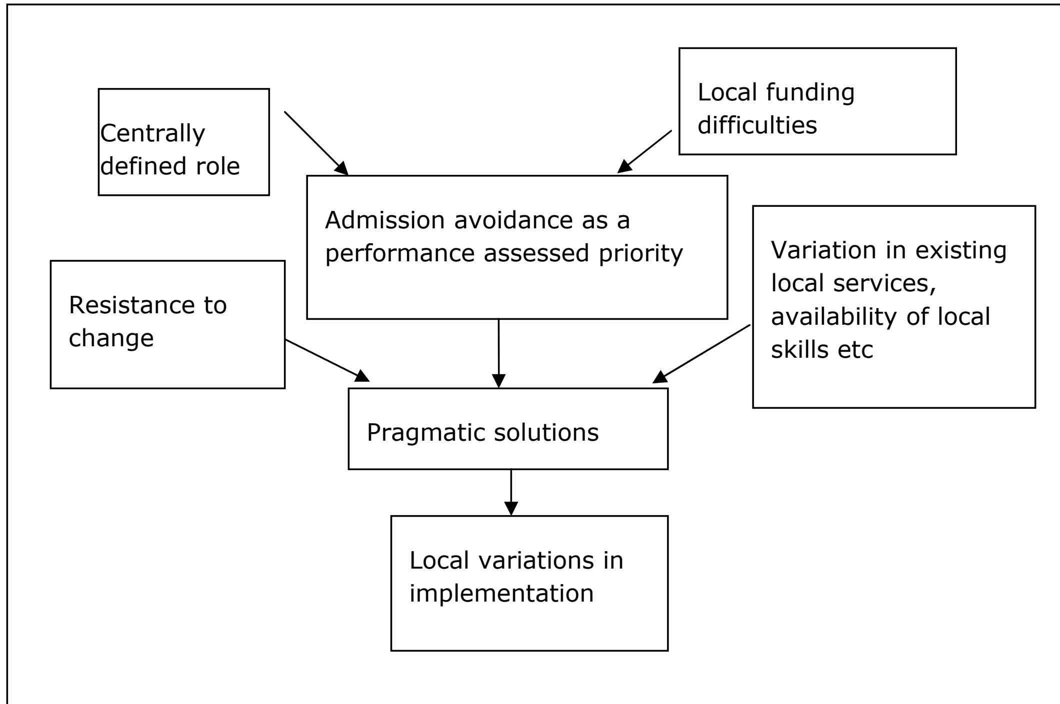
constraints, building on local relationships, local variations and local recent and historical developments to improve the management of care and services for people with LTC. The result of this level of pragmatism is widespread variation (Figure 4).

Figure 4 A model of influences on the local implementation of central directives



Pressman and Wildavasky (1973) suggest that implementation at local level of central government directives always results in variation through the dynamics of local power bases in decision making. The impression from this analysis is not that there are powerful influences subverting the intention of the central policy (although that may be true in some areas) but overall the multiple influences and contexts resulted in a more pragmatic approach to local decision making. The pragmatic approach invariably led to local variation away from the central directives. At a national level the DH workforce surveys suggested that the employment of community matrons did not reach anywhere near the target numbers for 2008 (Keen 2008). The central government monitoring of the PCT performance target of numbers of community matrons employed was withdrawn in 2008 (Healthcare Commission 2007).

This chapter has reported on the macro and meso-level investigation into the contribution of nurses in chronic disease management and as case managers as articulated in public policy. It suggests that the direct references are few although clearly the English policy networks were more receptive to naming roles for nurses than the Welsh networks were in this

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period. The advocated named roles for nurses cluster in *substituting* for other health professionals, mainly doctors, and *supplementing for weaknesses in the system of care delivery.* The survey has demonstrated the variation in local implementation of national policy. It also identified and confirmed the main groups of nurse case managers in primary care: community matrons, clinical nurse specialists, district nurses. In addition, the policy analysis and the survey identified variations e.g. nurse care managers designated to care homes. The next chapters report on the investigation at the micro-level in the case studies of the experiences of older adults receiving different forms of nurse case management.

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4 The case studies: overview and methodology

4.1 Introduction

The second phase of the study focused on the micro-level of service organisation and delivery through an in depth, comparative case study (Yin 2003). This phase addressed the study objectives through specific research questions:

- What is the impact of nurses' contribution to the experiences of patients and carers?
- What are the factors that enable nurse case managers to contribute most effectively to successful outcomes of care?
- What is the impact of the nurse case manager's contribution upon the cost, quality, effectiveness, and organisation of the care provided?
- What are the factors that sustain the models of nurse case management over time?

Multiple case study designs use several sources of evidence in order to triangulate data sources (Robson 2002) and capture multiple perspectives on the same issues (Bloor 1997).The elements of the comparative case study were:

- Investigating the patient experience over nine months as the recipient of different types of nurse case manager care through a) repeated semi-structured interviews with the patient , family carers, the nurse case manager; b) repeated use of validated measures with the patient and carer; and c) review of the nursing records and general practice records,
- Investigating the carer experience of nurse case management through a) semi structured interviews and b) validated measures at two points over nine months,
- Investigating the experience of the different types nurse case manager over nine months through repeated semi-structured interviews,
- Investigating the perceptions of nurse case management across a cross section of informants including services users, managers, commissioners and professionals through a stakeholder analysis (Brugha and Varvasovszky 2000) and documentary analysis (Rapley 2007).

This chapter presents: a description of the recruitment of the samples within the study sites, the methods of data collection, the method of analysis and concludes with the ethical review and NHS research governance permissions process and contextual information on the case study sites. Chapters 5-10 present the findings.

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4.2 Recruitment of participants

This section describes the method of recruitment of the nurse, patient, carers and wider stakeholder participants in the case study sites.

4.2.1 Recruitment of nurse participants

Nurse participants were identified through contact with managers within each PCT. The type of nurse case manager had to have been in place for a year or longer to avoid any early implementation effect from the creation of new services or roles. The managers were requested to ask staff, who they considered were providing a good standard of care, to indicate willingness to participate and be contacted by the study team. It was important that participation was voluntary. The managers were not involved once staff members, who had an interest in possible participation, were identified and referred to the researchers. Potential nurse participants were provided with information sheets and consent forms for the study, given time to consider whether to participate and a formal opportunity to discuss the study. Written consent was obtained. The aim was to recruit four different types of nurse case manager in each study site: a total of twelve nurses.

4.2.2 Recruitment of patient participants

The last five patients referred to each of the four participating study nurses in the three study sites were identified by the nurse and asked if they would be interested in participating in the study. The aim was to recruit 60 patient participants. The nurse made the initial contact with each patient and asked for permission for a researcher to make contact with the patient and explain the study. The patient was given an information sheet and consent form and allowed time to consider before further contact by the researcher. It was made clear that a decision whether to take part in the study or not was voluntary and did not affect patient care in any way. It was also made clear to those who agreed that they could withdraw at any point without having to explain why or affecting the care they received.

Patients who met the following criteria were excluded and not approached: those who were suffering from severe mental health problems, who were under the age of 60 or who had very limited life expectancy. People who had serious mental health problems were not included in this study as they were likely to be receiving case management from a mental health practitioner or key worker working within a model of mental health care that was not the focus of this study.

4.2.3 Recruitment of carer participants

At the first interview, each patient participant was asked to identify if there was a family member or friend who made a significant contribution to their day to day care i.e. an unpaid carer. The researcher then left the carer with the study information sheet and consent form, allowing two days before re-contacting to see whether the carer would be interested in participating. It

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was emphasised that the purpose of the carer participation was to reflect on the services that the patient and they received and not to discuss any personal information about the patient.

4.2.4 Recruitment of stakeholders

The stakeholder analysis aimed to recruit 10 stakeholders or key informants in each site to investigate the way in which nurse case management was perceived from an organisational, service and wider user perspective. The aim was to have informants from a wide range of perspectives including: across NHS and social care (e.g. medical consultants, GPs, social workers), managers, commissioners, and patient representatives (e.g. patient advisory groups and local voluntary groups that represent the interests of patients with long term conditions). These stakeholders/key informants were identified by the nurses in the study, by reviewing PCT documents on long term care strategies, and by invitation to local patient representative groups. The intention was to undertake 30 interviews, of which at least half were to be with patient representatives.

4.3 Data collection

The study used mixed methods of data collection: qualitative methods for interviewing and diary/informal record keeping as well as validated measurement tools for assessing health and social circumstances of patients. Although the sample size was small, these tools provided a standardised base to establish and compare the needs and profiles of the patient and carer population.

4.3.1 Data collection from nurses

Semi structured, face to face, interviews with each participating nurse were used at baseline and at 9 months. The data collection tools are presented in Appendix 3 .The first and last interviews gathered data on:

- Their professional history and education,
- Their patient caseload and other work activities,
- Their working practices,
- The team and organisation where they are located,
- Their work activities, collaboration and communication methods with other professionals, organisations and services,
- Their views on nurse case management and their job,
- Any other issues of importance to them.

Brief structured telephone interviews at monthly intervals were undertaken with each nurse to gather data on the nurse's experience during the intervening month and give details on their contact and activities with the 5 patients in that time. Each study nurse was asked to complete a generic diary to summarise their activities and the time spent on each one for every day of a typical working week. It was intended that this diary should be

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completed three times, once in the first month of the study, one in month 5 and once in the final month. In the event and following piloting, this was too time consuming for the nurses to do, so it was completed in months 1 and 9. The diary followed a basic template which could be adapted to the way individual nurses kept diary records.

Nurse case managers were also asked for copies of any internal documents relevant to their case management activities and job.

Data reported by patients/carers were checked through nurse case manager interviews at the start and end of the observation period. Information on tests conducted by nurse case managers was also obtained by this method and entered into the database to further inform the type of services delivered to patients. Plans for nurse case managers to keep diaries of their activities with each patient recruited to the study were dropped. Piloting of the diary (which asked the nurse case managers to record all visits, telephone calls, meetings, correspondence etc) showed the task to be too time-consuming and onerous.

Documents received were listed. Data from interviews were recorded and transcribed and stored in NViVO qualitative data handling software. Tapes were then deleted. Quantative data on nurse characteristics, caseload, nurse activities with patients, and recorded services used by the patient were entered into an SPSS database. All participants were given identification numbers and no personally identifiable data were stored in either databases.

4.3.2 Data collection from patients

Semi structured monthly interviews with each patient (face to face at baseline, at four and half months and at 9 months were undertaken; by telephone for the other months) to gather data on:

- How the patient was identified as needing the nurse case manager service,
- The patient's health and personal circumstances,
- The range of activities the nurse carries out with the patient, together with the amount of time in contact with the patient,
- The services received and resources used by the patient and their carers, including informal care, and care and support received that is not arranged or coordinated by the case managing nurse.

As part of these interviews validated tools were used to measure: quality of life (EQ-5D ™, Brooks 1996), dependency (Barthel Index of Assessment of Activities of Daily Living, Mahoney and Barthel 1965), ability to self care (Stanford Self Efficacy Scale, Lorig et 1989), cognitive impairment (6CIT, Brooke and Bullock 1999), and depression (Geriatric Depression Score, Sheikh and Yesavage, 1986). In addition, with permission, questions from the Picker Institute patient survey were adapted to measure patient experience.

The first and last interviews included all of the measures. It was anticipated that these interviews could take some time. As some patients were likely to

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be frail, these interviews were offered in sections to be conducted on two different days. Patients were provided with informal diaries structured to help patients to remember and record key events and encounters during the study period. The patients were encouraged to use this diary as an *aide memoire* when being interviewed by the researcher at different points in the nine month data collection period. Voice recorders were offered if preferred, instead of writing a diary. The data collection tools for the patients are given in Appendix 4

Data from interviews were recorded and transcribed and stored in NViVO qualitative data handling software. Tapes were then deleted. Quantative data on patient demography, health conditions, service use, and assessment tools were entered into an SPSS database. All patients were given identification numbers and no personally identifiable data were stored in either databases.

Patients were asked for consent for their GP to provide the research team with information from their medical records about their health and social care service use, consultations with the GP and treatments for the 12 months before they entered the study and nine months after they entered the study (21 months in total). They were still able to take part in the study if they did not consent to this element.

Data were recorded on a standardised form, with only the research identification number and then entered onto an SPSS database. As the study was adopted by the Primary Care Research Networks covering the study sites, participating general practices were eligible for service support costs for undertaking the data extraction from records.

4.3.3 Data collection from carers

Semi-structured interviews were undertaken with participating carers at two points. The first took place soon after the patient joined the study and the carer consented. The second interview occurred at the end of the nine months of the patient's participation. A topic guide for areas to be covered in this interview included: the types of care-giving the carer performed, perceptions of the nurse case management and of health and social care services offered and used. The Caregivers Strain Index was also administered. The data collection tools for carers interviews are given in appendix 5

Data from interviews were recorded and transcribed and stored in NViVO qualitative data handling software. Tapes were then deleted. Quantative data from the Caregivers Strain Index were entered into an SPSS database. All carers were given identification numbers and no personally identifiable data were stored in either database.

4.3.4 Data collection from key informants

Semi- structured interviews were undertaken with key informants either face to face or by telephone as preferred. An *aide memoire* for the topics to be covered in this interview included: perceptions of different types of

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nurse case management, local influences on the development of nurse case management, experience of the contribution and impact of nurse case management, factors supporting or inhibiting nurse case management. Key informants were also asked for copies of any internal documents relevant to their case management activities and job. Documents received were listed. Data from interviews were recorded, transcribed, and stored in NViVO qualitative data handling software. Tapes were then deleted.

4.3.5 Nurse attrition and reasons for missing interviews

Seventeen nurses were approached to take part in the study (table 10). Of these 16 initially consented (with one person not consenting due to health problems).

Table 10. Nurse recruitment to study

	Number
Approached	17
Recruited/consenting	16
Withdrawals	4
Remaining in study	**12**

Following initial consent one nurse changed her job and withdrew, one decided the commitment was too great because of her work load and one withdrew due to problems with her health. A fourth nurse who had initially consented did not then actively participate in the study and did not respond to any further contact. Her right to withdraw without giving reason was respected, and she was replaced by another nurse. The reasons for declining to take part or withdrawing from the study soon after consenting are summarise in table 11.

Table 11. Nurses reasons for declining or withdrawing

	Reason			
	Work load	Job change	Health	Unknown
Declining to take part			1	
Left study	1	1	1	1

During the course of the data collection two nurses left their jobs, and thus the study.

Among those nurses who took part in the study there were a number of personal and organisational factors that meant full participation each month of the study was not possible. Only two of the nurses were available for interview in all 9 months of the study (1 community matron, one nurse specialist). Ten of the nurses could were not available for interview for one or more months of the study because of lack of time and workload, particularly covering for the leave or sickness of other team members. Six

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of the nurses were not available for at least one month of the study because of annual leave: this was usually because taking annual leave usually led to an intensively busy period before and after the leave. Sick leave was another significant factor during the study, with 5 of the nurses having at least one month where they were unavailable because they were off work sick. Other significant issues were compassionate leave (2 nurses), study leave and study commitments (5 nurses) and leaving their job during the course of the study (2 nurses). Six of the nurses were unavailable for interview of at least one month for unknown reasons (table 12).

Table 12. Reasons for nurses non- availability for interview in 1 or more months

	Reason					
	Workload pressures	Job change	Health	Study	Leave (annual & compassionate)	Unknown
Community Matron	3		2	3	3	1
District Nurse	3	1	2	1	1	1
Nurse Specialist	2	1			2	2
Other	2	1	1		2	1

4.3.6 Summary of data collection undertaken

In total 118 people were recruited to the study: 18 withdrew and ten died. A total of 782 interviews were undertaken in the case study phase (table 13).

Table 13. Total data collection for study

Interviews conducted with	Number
Patient	352
Nurse	391
Carer	20
Stakeholders	19
Total interviews conducted	782

The case study phase was challenged by the slow process of recruitment and difficulties in retaining both nurses and patients for nine months. While this created difficulties for data collection, it reflected one of the strengths of case study research (Gomm et al 2000) in that it was grounded in the realities of the nurse case managers, the patients and also the service managers. The case study methodology allowed for exploration of the complex interrelationships, the multiple perspectives on the same phenomena and how the focus and delivery of the case managers' work changed and developed over time (Yin, 2003).

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4.4 Data analysis

Qualitative data were analysed by at least two researchers independently using a template methodology (Crabtree and Miller1992) which incorporated themes identified from the research activity of phase 1 (see chapters 2 and 3), using auto-coding functions in NViVO. In addition, a method of constant comparison (Strauss 1987) was used to identify any new themes. Differences in analysis between researchers were discussed and reconciled. Documentary analysis (May 1998) was undertaken using; a) the word search facilities in PDF documents if it was an electronic version; or b) a researcher reading the document to identify references to nurse roles in services for people with long term conditions in case manager roles. Evidence of service organisation, effectiveness, and factors supporting or inhibiting these roles was recorded on site specific grids and compared across sites for commonality. The outcomes from the standardised tools used in patient and carer interviews were formally scored, using the guidelines provided with each tool. These were then used, in conjunction with other data provided, with these tools to provide a measure of patient circumstances and likely levels of need. Quantitative data were analysed descriptively, summarising information collected on the patients and their use of services, carers, nurses, nurse activities. Summary measures of location (e.g. means/medians/proportions) and dispersion (standard deviations/percentiles) appropriate for the type and distribution of the individual variables were undertaken.

The data in the nurse diaries were collated and analysed under key headings to describe groups of tasks. These headings were guided by the Health Economist and were also informed by common patterns within the data itself. Eight task groupings were identified –time with non case managed patients, time with case managed patients, administration (including all record keeping), travel, management activities (team and staff ,management etc), liaison with other professionals (for instance, GP's, Allied health professionals and social work staff), Trust activity(including attendance at and representation on Trust based meetings or attendance at external events on behalf of the trust)and CPD – any personal continuing professional development activities undertaken by the nurse. Once the data for each nurse's diary had been analysed under these eight headings a mean value for the time spent on each task group by each nurse over the reported weeks was calculated to provide a value for a typical working week.

The data generated from the patient, carer, nurse interviews and GP records were brought together in two units of analysis: 1) the site, 2) the individual models of nurse case management across sites

Data for each of the four models of nurse case management were first analysed within the three study sites. Analysis was then undertaken within and across sites.

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Data from the case studies were then analysed to describe the features and impact of the nursing contribution. The analysis was guided by the findings of phase one and framed by the literature on:

- The organisation of health care work between and within occupational groups in primary care (Stacey 1988, Sibbald 2000, Peckham and Exworthy 2003, Iliffe 2008)
- The introduction of innovation and dissemination of best practice in complex adaptive systems (Dawson 1996, Rogers 1995 and Greenhalgh et al, 2005).

4.4.1 Economic analysis

A comprehensive economic analysis was undertaken to explore the costs of nurse case management. The specific aims of the costing study were:

- To investigate the caseloads and activities undertaken by nurse case managers recruited to the study, and to estimate cost per case-managed patient.
- To analyse the use of health and social services of patients recruited to the study by the nurse case managers, and to estimate total cost of service provision at patient level.
- To explore demographic and health factors associated with resource use and costs.

Full details of the methodology and results of the economic analysis are given in Chapter 7.

4.5 Ethics and research governance

The case study phase was given a favourable review by the NHS Southampton and South West Hampshire Research Ethics Committee in July 2007. Under the terms of the NHS Research Governance Framework, the University of Hertfordshire sponsored the research. Research and Development Governance approval was applied for separately in the three sites and finally agreed in August, September, and October 2007.

4.6 The case study sites

This section provides contextual detail about the case study sites. Following the survey in phase 1, 5 PCTs in 5 Strategic Health Authority Regions expressed an interest in participating in the next phase of the study. After further discussions and consideration of factors representing the greatest diversity in population, socio-demographic characteristics, and health economies, 3 agreed to participate. These study sites were: an inner urban area of a major city (site 1), a county area with small villages and different types of larger towns (site 2) and a coastal conurbation (site 3).

Site 1 PCT was coterminous with an Inner London Borough (population just over 200,000). The area has high levels of deprivation but also areas of relative affluence. The Borough’s Index of Multiple Deprivation (IMD) score

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for 2004 placed it among the worst 20 out of the 354 local authorities in England. The PCT was responsible for the commissioning of all local health services. The Borough was responsible for other local public-funded services, such as social care.

Site 2 PCT covered two District Councils (combined population 250,000) of a Shire County. The area had an agricultural tradition although service industries contributed substantially to the economic base. It is described as relatively affluent compared to national averages, with no wards being classed as significantly deprived. A two tier division of responsibility for publicly funded services existed between the District Councils and the County Council. The County Council was responsible for Adult Social Care Services and the Districts for services such as housing. The PCT was responsible for the commissioning of all local health services.

Site 3 PCT was coterminous with a Unitary Local Authority (population 250,000). The Authority was described as fast growing and economically strong in 2007. While there was relative affluence in many parts there were also areas of deprivation. Four wards were among the 25% most deprived in the country, according to their Index of Multiple Deprivation (IMD) score. The PCT was responsible for the commissioning of all local health services. The Unitary Authority was responsible for all other local public funded services, such as social care and housing.

Forty nine documents (table 14) were examined to provide the contextual information in this chapter.

Table 14. Documents examined to provide contextual information for each case study site.

Types of Documents Examined(n=46)
PCT Local delivery plans (all three sites)
Long term conditions strategies (PCT only or jointly with LA) (two sites only)
Operational policies for DNs, CMs or LTC nurses (two sites only)
Review or evaluation documents on any nursing services concerned with patients with long term conditions (all three sites)
Commissioning documents and service specifications related to community health provider services , including nursing , for people with long term conditions (two sites)
PCT annual reports in the last 3 years (all three sites)
Public health reports in the last 3 years (all three sites)
Local Authority Community Strategy including local strategic partnerships and Annual Reports (all three sites)

The following sections describe and compare:

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- Relevant demographic and epidemiological features,
- Health and social care commissioning and provision,
- Key events during the time of the case study.

4.6.1 The demography

The sites demonstrated a range of demographic characteristics. Site 1 had the highest density population and largest percentage from black and minority ethnic groups. The population aged over 65 was the smallest of the three sites but demonstrated a higher rate of income deprivation (Table 15). Site 2 had the lowest density population and smallest percentage of population from black and minority ethnic groups. It also had the highest percentage of people aged over 65 and lowest percentage in income deprived households.

Table 15. Comparative Population Data of the Case Study Sites

	Site 1	Site 2	Site 3	England Average
Retired Persons (% of the total population)	6.98	13	11	13.54
Density (number of people per hectare)	90.85	2.9	29.98	3.77
Pensioners owning their home	30%	75%	67%	68%
Population over 60 in income deprived households (%)	26%	10%	18%	16%
Recipients of Means Tested Benefits (% of residents)	20	5	14	12.9 (highest 31.1)
Population from Black and Minority ethnic groups (%)	40%	5%	10%	6%

Sources for Table 15: The Association of Public Health Observatories (2007), Audit Commission (2008), Office of the Deputy Prime Minister (2007), Office for National Statistics (2008)

The case study sites also showed differences in the epidemiological profile (table 16). Case study site 2 demonstrated a higher than national average life expectancy and a lower death rate than the national average from respiratory conditions, heart disease and stroke. All three sites reported a lower than national average rate of households with one or more persons reporting a limiting long term illness. Site 2 reported the lowest percentage of these types of households. In contrast, site 1 reported lower than national average life expectancy for men but above national average rates of death from respiratory conditions, heart disease, and stroke and rate of rates of hip fractures in people aged over 65.

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Table 16. Comparative site data on life expectancy, and selected morbidity and mortality

	Site 1	Site 2	Site 3	England Average (worst)
Life expectancy men (Years)	75.7	79.3	76.1	76.9 (72.5)
Life expectancy women (Years)	81.6	82.3	81.3	81.1 (78.1)
Deaths from respiratory conditions (age standardised rate/100,000 aged 35 +)	252	190	230	234.4 (366.5)
Early deaths :heart disease and stroke (age standardised rate per 1000,000 aged <75)	111.2	66	88.5	90.5 (151.3)
People with diabetes (% of adult population)	2.7	2.9	3.0	3.7 (5.9)
Older people: hip fracture (Age standardised rate per 100,000 aged 65 +)	642	544	516	565 (937)
Households with one or more person with a limiting long term illness (%)	28%	10%	31%	33.5%

Sources for Table 16: The Association of Public Health Observatories (2007); Office for National Statistics (2008), Sites Public Health Reports.

4.6.2 Health care commissioning

The three sites varied in the size of the local health care economy and spending on primary health care services and community health services (table 17). Some of these variations were historical so, for example, in site 2 NHS continuing care facilities and intermediate care services were commissioned from the Acute Trusts, whereas in Site 1 and 3 these were commissioned from community health provider services. Site 1 had a joint local authority and PCT commissioning strategy for older people. All three sites had some pooling of budgets between the PCT and the Local Authority for one or two services for older adults, usually in relation to facilitating early/timely discharge from hospital.

All three sites were developing practice based commissioning (PBC) at the time of the case study. The Department of Health survey of a sample of GPs in each PCT indicated that all were part of PBC groups and that in site 1 about 20 percent had been given indicative budgets, in site 3 about 30% and in site 2 about 80 percent (Department of Health 2008) .

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Table 17. Comparison of the health care commissioning budgets in the three site 2007/2008

	Site 1	Site 2	Site 3
PCT commissioning	Between £400-425 million	Between £600- 650 million.	£400 -425 million
Commissioned provider community services	75-80 million	45-50 million	65-70 million
Commissioning on primary health care services (including prescribing)	Between £80-90 million	Between £150-160 million	Between £80-90 million

Sources Table 13: PCT Annual Reports. Note figures are given within a range to protect anonymity.

Although there was some variation, the three sites were broadly similar in the national assessment of performance at the time of the case study (See table 18). Site 2 was considered to have failed to reach the performance targets for improving health outcomes for people with long term conditions.

Table 18. Comparison of the Health Care Commission rated performance in the three sites 2007/2008

Selected Healthcare Commission national categories and indicators	Site 1	Site 2	Site 3
Quality of Services	Fair	Fair	Fair
Use of Resources	Excellent	Fair	Good
Access to primary care professional and GP	Failed	Failed	Failed
Update registers for patients with coronary heart disease and diabetes	Achieved	Under achieved	Under achieved
Improve the quality of life and independence of vulnerable older people	Under achieved	Under achieved	Under achieved
Improve health outcomes for people with long term conditions	Achieved	Failed	Achieved
Service review of diabetes services	Fair	Fair	Fair
Service review of urgent and emergency services	Best performing	Better performing	Fair performing

Source for Table 18 Healthcare Quality Commission (2008)

Primary Care Trusts reported very different ranges of staff turnover rates during the case study period (NHS Innovations and Improvements 2008):

- Site 1 reported a average staff turnover of 22% (range <10 to >40),
- Site 2 reported an average staff turnover of 14% (range <12 to >17),
- Site 3 reported an average staff turnover of 12% (range <10 to >15).

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4.6.3 General practice

General practice services in Site 1 were characterised by higher than English average number of GPs per 100,000 population, in practices with lower than average practice list size. Site 2 offered a converse picture of general practice, with a lower number of GPs to population, higher than average numbers of other practice staff and larger than average practice list size (table 19).

Table 19. Features of general practice in the three sites

	Site 1	Site 2	Site 3	England
Number of general practices	40-45	60-65	45-50	
All GPs (excluding retainers and registrars) by headcount per 100,000 population	69	61	66	66.6
Average practice list size	5,000-5,500	>9,000	7,000-7,500	6,555
Mean number of other general practice staff (full time equivalents) per practice.	6	11	5	9
Patients aged 65 or over (per 1,000 patients)		145-150		151.7
Average general practice QOF points out of 1000 points available as a %	n/a	98- 99%	95- 96%	PCTs ranged from 891.1 points (89.1% of points available) to 991.7 points (99.2% of points available)

Sources for table 19: NHS Information Centre for Health and Social Care (2009); Local PCT reports and strategy documents for 2007/8

4.6.4 Community Services

Each site had broadly the same range of community services. Table 20 indicates the similarities and differences between those specifically involving nurses and concerned with adults with long term conditions. Some variation can be seen in commissioning between the sites.

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Table 20. Comparison of community nursing services between site

	Site 1	Site 2	Site 3
District nursing service	Yes 24 hour coverage, Geographical allocation to groups of GP practices in the daytime. Evening and night service 5pm – 8 am.	Yes 8am-8pm coverage. Geographical allocation to groups of GP practices in the daytime.	Yes 24 hour coverage. Geographical allocation to groups of GP practices in the daytime. Out of hours service 5pm-8am
Community matrons service commenced	2006	2006	2006
Clinical specialist nurses providing services outside of hospitals for adults	Cardiac, Diabetes, Respiratory Tissue viability, Dermatology, Palliative care, HIV/AIDs, TB.	Tissue viability, Macmillan Nurses	Cardiac, Diabetes, Respiratory Tissue viability, Palliative Care Macmillan Nurses Parkinson's Multiple sclerosis
Rapid response service i.e. short term health and social care team to prevent or shorten hospital admission	Yes	Yes	Within some specialist services
Community rehabilitation team (MDT)	Yes	Yes	Yes
Liaison nurses between hospital and community	No	Some (service specific)	Some (service specific)
Nurse/Nursing team for care homes (residential)	Yes	No	Yes

Sources for Table 20: PCT websites, operational plans, service specifications, annual reports and information leaflets.

4.6.5 Local Authority services

The Local Authority spending in site 1 for Adult Social Care was in the band of 70-80 million in 2007/8 compared to site 3 which was in the band of 130-140 million. It was not possible to disaggregate the County Council spending into the areas covered by Site 2. The provision of Local Authority provided support to older adults varied considerably between the three sites (table 21). Site 1 provided services to more people aged over 65 per 1000

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than the other two sites. Only site 2 achieved a performance level of the top 25 percent of Local Authorities on one measure.

Table 21. Comparison of selected Best Value Performance indicators relevant to older adults 2007/2008

Best Value Performance Indicators 2007/2008	Site 1	Site 2	Site 3	Average of national top 25% performing Local Authorities 2006/07
Number of households receiving intensive home care per 1000 pop. aged 65 or over	29	7	14	17
Older people helped to live at home per 1000 population aged 65 or over	124	80	97	101
Number of adults and older people receiving direct payments per 100,000 population	127	90	94	127
% of items of equipment delivered and adaptations made within 7 working days	90	85	85	93
% of assessments of Older People completed within acceptable waiting times (5)	81	85	83	88
% meeting acceptable waiting time for care packages following assessment for new older clients	92	93	90	93

Sources: Council Annual Reports 2007/2008

The key events in each site over the period of the study are summarised in table 22 below. Chapters 5,6,7,8,9,10 present the findings of the case studies.

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Table 22. Key Events in each PCT over the study period

Date	Site 1	Site 2	Site 3
2005			Creation of Community Matron service – 6 posts initially, planned for 12 after 18 months, primarily recruited from Band 7 District Nurse Team Leaders
2006	Creation of a team of 4 community matron posts and 1 community matron team leader. Most recruited from Band 7 district nurse team leaders. 8 district nursing teams. Band 7 district nurse team leader vacancies replaced with Band 6 District nurse team leader change in job description to become team leader.	Practice based commissioning locality groups established Creation of 6 Community Matron posts mainly recruited from band 7 and 8 local district nurses. Later in year, 5 new CM posts established as team is developed.	Practice based commissioning locality groups established Review of Community nursing services – increased focus on District Nurses providing specialist services and holistic assessment Consolidation of DN teams to form 16 larger teams with 160 WTE staff Increase of CM teams to 12 staff
National Autumn 2006	Restructuring of PCTS and SHAs nationally. Patricia Hewitt's announcement that the NHS would be in financial balance by March 2007		
Spring 2007	Practice based commissioning consortia established across the PCT Commissioners initiated review of district nursing service, community specialist nurses and community matrons Provider arm of PCT establishes its own arm's length organisation with a chief operating officer from the	District Nursing review in progress	District Nursing review Comprehensive internal review of all nursing services initiated Evaluation of organisational change

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Date	Site 1	Site 2	Site 3
	commissioning arm of the PCT		
National Summer 2007	The NHS Next Stage Review announced. Annual rise in NHS funding falls to 4% from 7.2%		
Summer 2007	District nurse teams are configured to cover practice based commissioning consortia Restructuring of local adult social care services	Community provider services re-organised.	Plans go ahead to restructure DN service increasing Day time DN working hours and contracting out of hours service to new provider
Autumn 2007	ENCAM Recruitment Starts Amalgamation of district nursing teams across the PCTs, 1 large team formed by joining 2 together to make 4 in total	ENCAM Recruitment Starts Plans to restructure DN teams in place	ENCAM Recruitment Starts
Spring 2008	Remaining 3 community matrons moved into the DN teams to give clinical support but also continue with own caseload. Introduction of Band 8A team coordinator to manage the DN team, and the CM. 50% clinical supervision and 50% screening of new patients. Evening and night community nursing service changed to a service covering from 8-10pm as part of main district nursing service.	DN teams restructured, Staff reapply for jobs.	CM teams moved from central base to community clinics to be closer to caseload
National Summer 2008	The NHS Next Stage Review : final Report and Vision for Primary Care Published		

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Date	Site 1	Site 2	Site 3
Summer 2008		Early plans for consolidation of DN teams with CMs	DN team hours extended, out of hours DN service contracted out.
Autumn 2008	ENCAM data collection ends	ENCAM data collection ends	CM team leader appointed. ENCAM data collection ends

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5 The nurses' experience of case management

5.1 Introduction

This chapter addresses the following study questions from the perspective of the nurse case managers:

What are the factors that enable nurse case managers to contribute most effectively to successful outcomes of care?

What are the factors that sustain the models of nurse case management over time?

What is the team structure the nurse is within, and how does it function?

What contributions are nurses making to the structure, process and outcomes of care?

In what ways are nurses working collaboratively with expert patient and user/carer groups?

What are the experiences of nurses?

What factors inhibit and facilitate the full participation of nurses?

The chapter commences with a description of the nurses who participated in this study and considers how they represented their involvement in the different elements of case management. The chapter concludes by examining the extent to which the nurses were able to embed a case management function within their work, and exploring the factors that supported, sustained, and inhibited this process.

5.2 Characteristics of nurse participants

Twelve nurse case managers were recruited to the study: four in each case study site. The three main models of nurse case management were: community matron (CM), district nurse team leader (DN) and clinical nurse specialist (CNS). Two other types were recruited a nurse practitioner (NP), employed in general practice and a care home specialist nurse (CHSN). Table 23 provides the overview of their educational background, caseload profile, sources of referrals, and their length of time in post.

The majority of the nurse case managers were graduates (8 of 12) and all had undergone further relevant specialist training either in community nursing or advanced practice courses in their specialist area. The length of time the nurses had been working in their current role ranged from 9 months to 13 years the (mean 1.6 years, median 2 years).The majority of the participants had worked in primary care settings for some time and only

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one participant (a clinical nurse specialist) had no previous community nursing experience.

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Table 23. Characteristics of the community matron participants and their caseloads

	Community Matron	Community Matron	Community Matron	Community Matron
	Generalist with specialist input for COPD	Generalist	Generalist	Generalist
Time in post	1 year	1 year	1 year	3 year
Background	Community	Acute and community	Acute and community	Community
Nursing qualifications	RGN, Dip Community Nursing, Degree Nursing	BA in Nursing, Diploma HF care, Coronary care courses, BHF CPD,	RGN, BA Nursing, Currently study for MSC in Primary Care	RGN, Diploma in Nursing, Courses in primary care, health
Number on case load	20 patients	42	32	30
Case load definer	Geographical south PCT	Urban area of PCT – majority case managed	Linked to 8 GP practices – all Case management	GP based – 2 surgeries
Case load profile	60+years, COPD, CHD, diabetes	CHD/HF, 45+ years	60+years, COPD, CHD, diabetes, Multiple morbidities, complex needs	CHD, Diabetes, COPD, Dementia – all housebound
Main referral source	Case finding – PARR	GPs	From within DN team	GPs
Other sources referrals	GPs, DNs, acute respiratory team, rehabilitation team, social services	GPs, DNs, Heart failure clinic, rehabilitation team, social services	GPs, DN team, Hospital clinics and consultant	Secondary care, carers, social services, dieticians

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Table 23 cont. Characteristics of the district nurse participants and their caseloads

	DN team leader	DN team leader	DN team leader
	Generalist	Generalist	Generalist
Time in post	9 months	3 years	3 years
Background	Acute & community	Community	Community
Nursing qualifications	BSc Health Sciences majoring in nursing, ITU course	RGN, Diploma in Nursing, Courses in primary care, health	BSc Special Practice(District Nursing) Dip Nursing EMB 1988, BSc Degree District Nursing
Number on case load	300 (whole team) 15 case managed patients	110 (whole team) 15 case managed patients	481 (whole team) 22 case managed patients
Case load definer	GP attached 2 practices	Whole PCT - partially case management	GP based – 2 surgeries
Case load profile	65+ years, COPD, Heart failure, diabetes	50+ years, COPD, Heart failure, diabetes, tissue viability	CHD, Diabetes, COPD, Dementia – all housebound
Main referral source	GPs	GPs	GPs
Other sources referrals	Secondary care, self referrals, carers, social services, rehabilitation team	Secondary care, carers, social services, dietician	Secondary care, carers, social services, dietician

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Table 23 cont. Characteristics of the nurse specialist participants and their caseloads

	Clinical nurse specialist	Clinical nurse specialist	Clinical nurse specialist
	Disease specific	Disease specific	Disease specific
Time in post	3 years	13 years	1 year
Background	Acute care	Community	Acute and community
Nursing qualifications	RGN, BA Cardiac care, ITU and coronary care courses	RN Dip District nursing, N18	RGN, RM, Dip Asthma, Nurse prescriber
Number on case load	75	490 – all patients(team) 26 case managed patients	610 – all patients(team) 60 case managed patients
Case load definer	Geographical whole PCT	Geographical – ½ PCT	Whole PCT
Case load profile	CHD/HF, 65-70 years	Tissue Viability	COPD
Main referral source	GPs	Vascular Consultant	GPs
Other sources referrals	Secondary care, dietician, nurse specialists, DNs, CMs	GP surgeries, District Nurses, CHD nurse specialist, from within the NS team	Hospital COPD clinic and consultant, DNs

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Table 23 cont. Characteristics of the other types of nurse case managers and their caseloads

	Care home specialist	Nurse Practitioner
	Specialist (older people)	Generalist
Time in post	5 years	4.5 years
Background	Community	Community
Nursing qualifications	RGN, MSC Advanced Physical Assessment	RN,BA Nursing, Dip Nurse Practitioner
Number on case load	621 whole team 102 case managed	43
Case load definer	Whole PCT	GP attached – 22 GPs in the practice
Case load profile	Care home residents with complex health needs	COPD,CHD Stroke – all housebound
Main referral source	Care home referrals	GPs in practice
Other sources referrals	GPs, Case finding	None

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5.3 Support and training and organisation for the case manager role

There were different levels of training and support for the nurse case managers across the three sites, as summarised in Table 24. The nurses had varied levels of access to mentors and clinical supervisors. For many these contacts were intermittent and unstructured although the nurse case managers also talked about drawing support from colleagues and having contact with their immediate manager. The care home case manager had no access to mentorship or clinical supervision. Only one case manager held any responsibility for a budget. All the nurses had access to computers but access to administrative support varied considerably from none to a full time post supporting the case manager. Nurses in site 3 had the most administrative support.

The greatest amount of training and education was reported by the community matrons, who had all either just completed study modules in assessment and chronic disease management or were doing this alongside their daily work. They observed that this latter arrangement could negatively affect continuity of care for their patients and professional development activities could be stressful when course deadlines coincided with busy times at work:

"It's been really tough and stressful getting the studying done, and they have changed their requirement for all CMs to study for an MSc now. The two of us who did it found it all too much, so they are now reducing the requirement to needing to study to MSc levels only for named modules". Community matron

In contrast the district nurses acting as case managers, relied on informal learning from other nurses. This group received little extra professional updating and skills development in the areas of assessment skills, symptom management, and coordination of care.

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Table 24. Case managers' access to administrative support and ongoing training across the three sites

Site 1	Computer and email access	Administrative support	Budget responsibilities	Training and education since taking up role
CM	Yes	None	Manager holds budget – she is aware of it	Physical assessment skills (independent organisation), COPD and CHD training – in house. all community based.
DN	Yes	None – but should have 0.8 administrator	Yes	In house courses on staff management
CNS	Yes	Shared administrator	No	MSc Cardiology
Nurse Practitioner	Yes	Yes – full time	No	Short courses (external organisations)
Site 2				
CNS	Yes	Shared secretary	Yes in collaboration with manager	In house
CM	Yes	Shared administrator	No	Nurse prescribing In house and seminar updates Advanced practitioner course and advanced clinical assessment
DN	Yes	No	No	
CM	Yes	FTE shared with CMs	No	Extended prescribing and wound care course
Site 3				
CM	yes	0.5 FTE	No	MSc course
Care home CM		1 FTE	No	Conrane* training with CMs
DN	Yes	1FTE administrator for the DN team	No	In house
CNS (left study)	Yes	0.5 administrator for team	No	Conrane training, nurse prescriber

*Conrane training: A training package for community matrons offered by Conrane Consulting. It includes teaching and support materials on population risk profiling, patient assessment and care planning, change management and evidence based management guidelines

5.3.1 Organisational structures by nurse model

At practitioner level the organisational structures and systems for managerial oversight and support varied according to each case manager model (Tables 25, 26, 27, 28). The district nurses, one of the clinical nurse specialists and care home case manager were leading a team of less and differently qualified nurses. For these nurses working as a case manager was combined with wider team management responsibilities. Across all the models access to clinical supervision and mentoring support was erratic. At the beginning of data collection community matrons were working independently and met with other community matrons to provide informal support and cover for annual leave.

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Table 25. The responsibilities and support of the community matrons

	CM 1	CM 2	CM3	CM4
Manager	Adult community care manager	Community matron manager	Community matron Manager	Community nurse manager
Work as part of team?	Yes	Work independently, supported by peers	Work independently, supported by peers	Work independently, supported by peers
Size of team	4	12	12	6
Composition of team	4 CMs	12 CMs	12 CMs	6CMs
Team working	Weekly meetings Provide cover	Meet regularly Provide cover	Provide cover	Provide cover
Clinical support & supervision	Consultant , CMs Psychologist gives clinical and personal support every 2 weeks	GP, Consultants. Group clinical supervision meeting	Clinical support group Consultants GP from another surgery	None, but is planned for future
Mentor	Informal support within team	None	Ongoing and informally from manager, peer buddying system.	Informal support within team
Contact with other professionals and organisations	Consultant, GPs, Social worker, Rehabilitation team, Chronic Disease team, dentist, dietician, wheel chair service.	GPs, physiotherapists, OT's, speech therapists, dieticians, specialist nurses, consultants. Breathe easy and age concern	Physiotherapists, OT's, dieticians, speech therapist, chiropodist,specialist nurses, Consultants. Limited working with DNs - increasing. Age concern, Breathe Easy, MS Society	GPs, district nurses, physiotherapists, occupational therapists, adult services, age concern, Carers society, Consultants. Contact with anyone who may be able to help the patient.
Other responsibilities within organisation	None	End-of-life group, gold standard group, nurse prescriber form	COPD group, elderly care group	None
External responsibilities	Community centres for older people	Talks to voluntary organisations	None	None

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Table 26. The responsibilities and support of the district nurse team leaders

	District Nurse 1	District Nurse 2	District Nurse 3
Manager	Change Implementation Manager	The district nursing manager	The district nurse manager and clinical supervisor
Work as part of team?	Yes	Yes – but case management work done independently of team	Yes
Size of team	5	4.5 + 1 temp	5
Composition of team	Manager 1 agency registered nurse band 5, 1 registered nurse band 5 2 band 3 trainee assistant practitioners	Manager 2.5 staff nurses 1 health care assistant 1 healthcare assistant on temporary secondment	Manager 1 band 6 4 band 5 (2 are job share)
Team working	Monthly team meetings Manager meets daily with team	Meet daily Monthly small team meeting 3 monthly meeting with all DNs in area.	Meet daily; actively share work, notes, and records. Telephone contact as needed
Clinical support/supervision	Line manager Other team leaders	None formally Informally through colleagues and line manager.	Clinical manager
Mentor	Manager	None formally Informally through mentor of previous post	Practice development facilitators, practice educators
Contact with other professionals and organisations	GPs, Social workers, health trainer	OT's, GPs, physiotherapists, social workers, hospitals, hospices, bank nurses, continence specialists, Age concern, Alzheimer's Society, carers Association CMs in same building but little contact	Macmillan nurses, social workers, community matrons, diabetes nurses, RNS, Carers association, Alzheimer's Association
Other responsibilities within organisation	Trust equipment store, Flu management group for PCT	Gold standards framework	
External responsibilities	None	None	None

Table 27. The responsibilities and support of the clinical nurse specialists

	Nurse specialist 1	Nurse specialist 2	Nurse specialist 3
Manager	Head of Children's and Adult Primary Care Support Services for the PCT	Community Nurse Manager	Clinical lead/manager
Work as part of team?	No	Yes	Yes
Size of team	N/A-	7 (6 part time)	13
Composition of team	N/A	Manager 2 clinical support nurses 2 clinical co-ordinators 1 clinical nurse 1 admin	2 Lead clinical nurses (band 7) – 1 is team leader, 1 senior manager with 1 day a week clinical time (band 8a),3 clinical assistants (band 3), 2 specialists nurses (band 6), 1 OT (band6), 2 senior physiotherapists (band 7),3 administrative assistants covering 8-4.30 7 days a week
Team working	N/A	Work closely and meet as needed.	Daily contact, handover and liaison meeting Monthly formal progress meeting Team decisions except for difficult or major issues lead nurse' and senior manager discuss.
Clinical support & supervision	Trust clinical support group Consultant, members of the Chronic Disease Management team	Monthly clinical supervision group Local condition based group	Manager GP, Consultant
Mentor	None	Community Nurse Manager	None – no formal supervision
Contact with other professionals and organisations	GPs, consultant, dietician, district nurses	District nurses, GPs, some community matrons, Consultants Social services, Carer group, Physiotherapy	Others in the interdisciplinary team, Community and specialists nurses, GPs, Adult services, Carer group, Breathe easy
Other responsibilities within organisation	Runs specialist courses for DNs, informal teaching of GPs. Clinical governance, NCL, Specialist groups	None	None
External responsibilities	Talks to community groups	None	None

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Table 28. The responsibilities and support of the other nurse case managers

	Care Home Specialist Nurse	Nurse Practitioner
Manager	Community Nurse manager	The managing GP partner
Work as part of team?	Yes	Yes
Size of team	8.2	Not specified
Composition of team	1 team leader (band7) 3 Full Time band 6, 1 0.4 band 6 1 End of life care facilitator (band 7) 1 full time equivalent (2 people) administrator 1 full time mental health nurse, 2x 0.4 physiotherapists.	Bridges several teams (GP/practice nurses, HCAs, Admin)
Team working	Weekly team meeting and ongoing contact	Practice nurses meet every 2 weeks and as needed.
Contact with other professionals and organisations	Team is interdisciplinary. Liaise with other services and practitioners as needed Age concern	District nurses, community matrons, chronic disease dietician, respiratory nurse specialist, diabetic nurse specialist, social services social services
Clinical support/supervision	Consultants, Specialist nurses	Mentor, GP
Mentor	None	GP
Contact with other professionals	The team is interdisciplinary and we liaise with other services and practitioners as needed – we have a broad remit, which makes this easy to do.	District nurses, community matrons, chronic disease dietician, respiratory nurse specialist, diabetic nurse specialist
Other responsibilities within organisation	Community Nursing service, infection control, safeguarding vulnerable adults.	QOF, smoking cessation
External responsibilities	None	Out of hours service

Over the nine months of this phase of the study in all three sites, the different case management services were subject to more than one review and numerous organisational changes. This had a direct impact on how and who the nurses worked with and their networks of support and

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communication across their organisation. Apart from the nurse practitioner, based in her employing GP practice, by the end of the period of data collection, no case managers in this study was either working in the same location and/or with their original networks of colleagues.

5.4 Views and definitions of case management

The nurses worked within different models of case management; but only the community matrons were wholly defined by this role and all its elements. Case management was one component of the work of clinical nurse specialists, district nurses, nurses working with care homes and the nurse practitioner, with the nurse practitioner only giving half a day a week to the case management of 43 patients (table 23).

At the centre of the nurses' narratives was their dual contribution of providing direct (face to face) care whilst also ensuring that patients received services that could optimise their health and wellbeing. Distinctions were made between 'hands on' nursing work and case management work, which had implications for how nurses interpreted the priorities and focus of their activities and who else they involved in their patients' care. Liaison and representation of the patients' needs was sometimes described as 'not nursing' but nevertheless an essential part of the case manager role.

"I see my role as mainly ensuring that patients gets the care they need whether it be from the district nursing team, specialists, adult services or other services such as charities, palliative care services or Macmillan nurses…A lot of what I do is overseeing the care of patients, I liaise a lot with GPs, sometimes I feel like it's more of an advocacy role than pure nursing." Community matron

One of the nurses had taken up the community matron role because her previous work as a district nurse team leader had removed her from patient contact. In contrast another nurse had rejected the community matron form of case management because it did not conform to her understanding of nursing:

"I didn't like the work as a community matron - it was too much like being a social worker. I prefer to have a clinical role". Clinical nurse specialist

Although there was a potential tension between providing "hands on" care and acting on behalf of the patient, most of the nurses recognised that acting as a case manager meant co-ordinating and managing services as well as providing them.

"For me it's about making sure that each patient, treated as an individual, gets what they need in the right way for them." Community matron

"Facilitating services and support for people with complex needs so they can live life in the best way possible for each person." District nurse

"Looking at everything that patients needs and facilitating services to make sure these services are met." Clinical nurse specialist

The majority of nurses emphasised that building a relationship with patients was central to their case management activities. A minimum requirement was good communication between the patient and the nurse.

There were also explicit clinical goals, such as improving patients' lung function, wound healing or good symptom management through medication review. However, the policy-related goal of reducing unplanned hospital admissions either did not feature in the nurses' discussions of the focus and purpose of their work or was implicit rather than explicit in the discussions of what they were trying to achieve through case management. At the patient level of care preventing hospital admission the emphasis was on the nurse patient relationship.

At sites one and three, two nurses identified themselves as case managers, but held very different approaches to how they interpreted their role and responsibilities. These were the care home case manager and the nurse practitioner. For the care home nurse case manager and her team their case management work was mediated through others. This was in effect case management by proxy and the nurse described how reliant they were on care home staff being willing to put them in touch with residents likely to benefit from case management and work with their suggestions and guidelines for care.

The nurse practitioner described her work as identifying services likely to benefit older people, arranging diagnostic and screening tests and educating patients on how to manage technical aspects of their care, for example using an inhaler and monitoring blood sugar. Unlike the other models described, her emphasis was not on establishing a long-term relationship with patients. She saw the particular focus of her role as ensuring that a patient group that was often overlooked in general practice, received services it was entitled to and likely to benefit from. The introduction of the Quality and Outcomes Framework (QOF) and the inclusion of these patients in the figures for chronic diseases disease management in general practice had provided a fresh impetus for her work. The nurse practitioner did not appear to have a role in monitoring and reviewing the care her patients received. It is debateable whether she was working as a case manager, even though she conceptualised her work with this group of 43 patients that way.

5.5 Accounts of managing the patient caseload

The type of nurse case management model determined the size of the caseload (see table 23). The variation in the caseload size across the models of nurse case management was indicative of the focus of the care (disease or people at risk or people with ongoing needs), the length of time the service had been in place and how well the service was known to other referring services. This was particularly true for the Community Matrons. They were working full-time as case managers but their caseloads reflected the fact that they were still comparatively new in the primary care organisation, the complexity of their patients' needs and the 'high intensity' patterns of working and visiting that the model used. However, the district

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nurses and some of the clinical nurse specialists that initially appeared to have larger caseloads described their case management activities as being restricted to a sub-group of older people who had been identified as being at particular risk or to have complex needs. For example, one district nurse described how she was the 'named nurse' or case manager for 20 patients but her team was responsible for 180. Similarly the care home case manager was actively involved in managing the care of 25 older people from the 110 people her team were case managing, although the potential pool of people who could be referred to her team was estimated at approximately 620.

Seven case loads were defined geographically (by PCT) and the remainder were GP attached. The three district nurses were all GP attached although in site 2 the district nurse was liaising with 8 different practices and the nurse practitioner in site 1 was working with 22 different GPs. This would suggest these nurses were GP, or health centre aligned rather than working with a known group of GPs.

The nurses in this study received referrals from a wide range of sources. Decisions about who could be a 'case' were based on locally agreed criteria, such as diagnosis or health problem, level of case complexity and location. These types of criteria were more explicit for community matrons than other case managers. The community matrons in all three sites were actively engaged in case finding activities using criteria that related to numbers of conditions, medications, unplanned hospital admissions, GP contacts, as well as the patient's perceived level of vulnerability. Some nurse case managers applied their criteria more strictly than others and there appeared to be more flexibility and fluidity of definition when the case management function was part of wider caseload. District nurses talked about 'picking up' patients who did not quite fit the community matron criteria and gave examples of referrals from social services of patients being "offloaded" on to them who had complex needs but for whom no obvious nursing care was required.

"I am assessing 4 new patients, but one of them may be too ill for what I can do for him. The trouble is that he doesn't fit in the community matron's remit either, so I may end up taking him on anyway." District nurse

For all the case managers the composition and their involvement with patients on their caseload were constantly changing. Over the period of data collection it was an ongoing (and unresolved) point of discussion as to what an optimum caseload size was for a nurse case manager. None of the caseloads reduced in size during the period of the study.

The case manager who worked as part of a leg ulcer treatment service had a role that was predicated on working within a nurse-led clinic based service that transferred patients with intractable and complex problems to her care. When their care needs were less acute the patient would return to the routine clinic management. This nurse also had line management responsibilities, was developing an extended service, provided ongoing education and support to clinicians working in the clinic and to the wider PCT, including community matrons. By the end of data collection her case

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management role was diminishing and she was identifying other nurses to assume responsibility for her caseload.

The district nurses also described how the case manager role was fitted within the overall workload. For some it was difficult to fulfil their case management responsibilities alongside the other demands on their time. One team leader, who had case management responsibility for 15 patients, described how three members of her team were beginning to assume case manager responsibilities for three patients with the intention of developing and spreading these responsibilities across the team. However, unlike the community matrons, there was no additional training or support to help these less experienced nurses assume these responsibilities. For the district nurse the case manager role could not be a discrete role defined by knowledge, skills and experience. The solution to the increasing workload demands was to involve more junior nurses in case management work and presumably become more involved in the supervision and guidance of staff, it was not to employ more nurses with case management expertise.

Most community matrons and community nurse specialists did not expect to discharge patients to other services. However, by the end of data collection community matrons in two sites were reviewing the pattern of contact they had with patients and were introducing a system for differentiating between patients with acute needs, those needing regular review and those who were stable and needing minimal attention, This appeared to be 'mimicking' the approach used by the district nurses and the clinical nurse specialist in site 2.

Community matrons and clinical nurse specialists were exploring ways to increase referrals to their service. The limitations of the PARR (Patients at Risk of Readmission) tool were highlighted by all the community matrons they noted the importance of identifying patients who had complex needs but who did not have a history of hospital admissions. Community matrons talked of pressure from managers, and the need to increase "productivity" but without the PARR tool there were no systems in place to help them achieve this, and they were reliant on others to refer patients to their service:

"I think one of the issues is that there are only so many people at the top of the triangle and now we are delving deeper and finding more hidden patients with needs that may be just as complex as those who admitted to hospital 3 times or more in a year, but for whatever are not know to the services. I have a problem because my main GP tends not to refer to me, but I'm working on it slowly and hope that he may do more as time goes on…..our main problem seems to be in helping other services understand what we can do for their patients and that we are a distinctive and independent service in our own right." Community matron

The following sections consider the nurses' accounts of their activities within a case management framework.

5.6 Nurses' case management activities with patients and

carers

A list of all the recorded activities by the CM, CNS and DN case managers was established at baseline (Table 29) and grouped according to the categories identified in the policy review (see chapter 3) . Community matrons performed the greatest range of activities, 27 out of the total of 30 recorded for the main three nurse case management models, compared with 13 and 9 for the nurse specialist and district nurse respectively. Each activity was then grouped according to a list of activities advocated for nurse case managers within policy and guidance. This allowed for further comparison of the different models of nurse case management in relation to their respective roles and modes of operation.

In the interviews the nurses provided further information on their activities which following analysis was grouped into the following areas: assessment and review, care provision, co-ordination activities, technical care, palliative care and patient/carer education. There was a discrepancy between what the district nurses recorded as activities completed for the patient and what they reported they did in the interviews.

5.6.1 Assessment and review activities

All the nurses used standardised assessment tools at the point when patients were admitted to their caseloads. Over the nine months of the case study nearly all the assessment tools used by the nurse case managers had been modified or changed by the practitioners. These assessment tools were an eclectic mix and differed within and between the different case management models in the three sites. Assessments could be based on Single Assessment Process (SAP) documentation agreed with the Local Authority or an extension of the usual assessment used in the PCT for all patients admitted to a community nursing case load. Some community matrons and the nurse practitioner used imported US systems of assessment, such as those used by United Health (Evercare) or equivalent tools.

The community matrons had all received training in advanced assessment skills. Clinical nurse specialists used structured assessment tools related to the disease they specialised in and a disease management process. Most of these they had developed themselves or tailored to fit how they worked with patients. One of the CNS and two of the community matrons used locally agreed integrated care pathways for particular symptoms, such as the management of breathlessness. The nurse working as part of the care home support team characterised her work as starting with a clean sheet and having to develop methods of assessment, review, and recommendation that would be acceptable to the care homes with whom they were working.

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Table 29. Nurse case managers' recorded types of activities for patients

Activity	Recorded by case managers		
Monitoring and review technical activities	CM	CNS	DN
Take BP, pulse, temp, O2 sat, weight, Blood test	√	√	√
Blood glucose check	√		
Assess COPD, peak flow,	√		
Spirometry			
Ongoing review	√	√	√
Prescribing and providing treatment	CM	CNS	DN
Chest physiotherapy	√		
Pain management	√		
Medication management	√	√	
Give nebulisers	√	√	
Prescribe medication	√	√	
Apply dressings		√	√
Provide education, information and support , self care to patients and carers	CM	CNS	DN
Teach deep breathing exercises	√		
Health education and advice	√	√	
Telephone advice	√	√	
Visit in hospital	√	√	
Liaise with carers	√	√	
Self management education	√		
Provision of daily living aids	√		
Attend consultant clinic with patient	√	√	
Assessment of problems and planning			
Chest examination	√	√	
Ongoing assessment	√	√	√
Provision of emergency care plan			√
Be contact point / signposting to others			
Liaison with physiotherapist and OT	√		√
Be member of MDT providing services to people with LTCs	CM	CNS	DN
Liaise with GP, CNS for specialist advice, DNs	√		√
Joint working with social services	√		

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5.7 Role drift and expanding teams

Community matrons and district nurses talked of being very careful not to overwhelm the patients with numerous questions and being cautious about leading patients to feel they were the subjects of assessment. Several intimated that the assessment documentation was not the main source of information for how they worked with the patients, preferring to rely on getting to know the patient and their carer over time:

“We carry out a holistic assessment based on the referred need of each patient. This is not a formal process; it is something I carry in my head and the way that I think. We do have standard tools but all of the time I am using my experience and asking the little things that can make a difference to making sure that patients get the care and support they need, without firing hundreds of questions at them” District Nurse

“We have a standard assessment tool to use for new patients. This looks at all the issues the patient may have including the health and social needs. I may not do every part for the assessment for every patient, because some of it is not relevant to some people. We're developing a new form of assessment which is a little less rigid and more workable with individual people - . This should be rolled out in the next few months.” Community Matron

At time point one in the study there were only a few examples of joint assessments or visits to the patients with other professionals being undertaken. Clinical nurse specialists talked of joint assessments with dieticians and other nurse specialists and with the palliative care team. However, the clinical nurse specialists also talked about their isolation and the need to be very experienced because they could not easily involve other professionals, such as hospital consultants, or other specialists in the assessment process.

In all three sites assessment tasks were divided between different groups of nurses. For example, community matrons would undertake a comprehensive patient assessment but would leave wound and continence assessments and patient referrals for medication blister packs to the district nurse, or they might involve clinical nurse specialists for assessment of medication.

None of the practitioners over the nine months had achieved an integrated system of shared documentation with other health or social care services. Most of the nurse case managers had multiple patient records and notes left in more than one location: in the patients’ homes, at the GP practice or outpatients’ clinic and at their office base. For case managers working in newly created roles where they were not well known in the organisation, this was a particular problem. This community matron described some of her frustrations at trying to maintain communication with other services:

“We are very reliant on patients telling us if they're going into hospital because is no system between hospitals and community matrons that does that yet. We've tried taking the patients’ notes and files into hospital but

these sometimes get lost. We end up relying on the patients taking and bringing them back but that doesn't always happen. It's pretty handy for the hospitals to have these notes, and bad for us if they get lost." Community matron

The nurses, who were GP attached or aligned, were able to access GP records and for some, add to the GP patient electronic records. The nurse practitioner and one of the community matrons reported being involved in completing general practice QOF data for their patients. We found no evidence of GPs actively using or referring to the nurse case managers' documentation and there were a few instances of where blood tests for the same patients were requested by both nurses and GPs.

There were two different IT operating systems in one site, which meant it was not possible for the district nurse case manager to access Single Assessment Process (SAP) documentation completed by social workers about the same patient. The nurses reported that shared documentation was desirable but very difficult to achieve in their areas. The nurses' assessment and review work was done independently and parallel to the other services involved, even in the few examples of joint visits and case conferences The district nurse in site one had been using 9 different assessment forms. By the end of the period these had been reduced to one set of notes in a patient's home and one with the nurses. However, she described that the whole change process to achieve this had been "*overwhelming*".

Central to the case management process is the ongoing review of the patient's condition and the services that they are receiving. The majority of nurses reported reviewing patients and their care every three months regardless of the model used. It was not clear from the interviews how their reviews influenced their or anyone else's decision making. One district nurse case manager commented that it was difficult to review patients or define success, if successful care '*is when nothing untoward happens, the patient is stable and there are no hospital admissions'*.

In contrast, a clinical nurse specialist working with patients who had COPD talked about developing action plans for her patients. These plans were then used as a basis for review and decision making as to whether the patient was benefiting from the service or should be referred to other services such as palliative care. She was unusual amongst these nurses in having such a structured approach to care delivery. She did not see her service as having an open-ended commitment to the patients:

"Once we have assessed patients, and dealt with their most urgent needs we formulate a plan of action, rather than a formal care plan. Our aim is to help each person manage their COPD as best they can. We do this by a mix of physical and medical therapy, education, maximising the benefit of medications, and pulmonary rehabilitation. ...We keep people on our caseload while their disease is still changeable and where we can have a positive effect. At present we refer onto other specialist nurses for palliative care – where respiratory disease is too severe for us to be able to have an impact." Clinical nurse specialist

Over the nine months of data collection there was a change in the practice of the community matrons and some of the clinical nurse specialists. They described becoming more involved in undertaking shared assessments and reviews with other nursing services and GPs. The reasons for this appeared threefold; 1) the need for expert input from others, 2) in order to manage the caseload and refer patients to other services, and 3) because their role and work were becoming better known in their local PCT and linked health social care and third sector organisations. Nurses also spoke of having increased confidence in how they worked with others and how this may have affected their willingness to involve other services and clinicians.

5.7.1 Care provision and co-ordination activities

Community matrons, clinical nurse specialists and district nurses recognised how long it took to achieve a change in patients' situation, and spoke of it taking between six months to a year to build up relationships with patients and carers and for patients to stabilise or show signs of improvement. Equally it took time for patients to be willing to accept services and there were several examples of patients refusing referrals for social care or equipment that were subsequently accepted by the end of the data collection period. Chapter 8 summarises the range of services to which nurse case managers referred patients.

Even when there was a relationship of trust and willingness to accept the case manager's input there were examples of how long it could take to organise and co-ordinate the care a patient received, One community matron, said that for each new patient on to her caseload she estimated it took four days to organise and put in place the services they needed. This intensity of involvement could be continuing. The clinical nurse specialist in site one described how it had taken three days to organise a change in a patient's medication. It had involved making sure the patient understood the new regime, liaising with the social care staff and district nurse and finding a pharmacist that would set up the appropriate blister pack.

A nurse case manager could increase a patient's access to other services. For those services that were not already part of the case managers' immediate team or network (e.g. community matrons to district nurses or clinical nurse specialists to outpatient services) this was invariably achieved by initiating the referral via a GP or having fast track access to the patient's hospital consultant. In these examples the nurses' role was to make existing (invariably medical) services more responsive to their patients' needs. This was an example of nurse case management supplementing and improving service provision for patients who had difficulty making their needs known.

Community matrons and clinical nurse specialists were careful to inform GPs and hospital services about the patients through email and by attending team meetings. It was less clear how the nurse case managers monitored services or received feedback on progress and decision made by others. Communication between professionals was one way. The patient was often the main source of information for the case manager about whether

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services had been received and how effective they had been. There was an example of a community matron meeting with a district nurse team leader at the patient's home to review the quality of the care being provided, but this appeared to be unusual and was initiated because of concerns about the quality of care being provided by the district nursing service. The nurse practitioner in site 1 referred a patient to the district nursing service for regular monitoring of her blood pressure, but over the nine months of data collection did not appear to expect feedback and did not follow up the referral when the patient did not receive the service.

5.7.2 Technical care

There was overlap between the different case manager models in terms of monitoring, with some or all of the nurses involved in monitoring patients' condition (e.g. spirometry, BP, blood tests), reviewing medication, wound care, prescribing and use of nebulisers. The biggest differences were the place where care or treatment was provided and the level of expertise of the nurses involved.

The clinical nurse specialists worked out of clinics and also did some home visits, whereas district nurses' and community matrons' main focus was on providing care in patients' homes. Clinical nurse specialists and some of the community matrons had developed a particular expertise in disease management that meant they coordinated and reviewed very specific elements of a patient's care and would substitute for GP or hospital based care. This was particularly evident for patients with COPD and CHD. This description captures the range of one community matron's work for people with COPD:

"Our aim is to help each person manage their COPD as best they can. We do this by a mix of physical and medical therapy, education, maximising the benefit of medications, and pulmonary rehabilitation. We have also started a special practice clinic run by specialist nurse practitioners. We provide rapid response cover for those that need it – and this is why we work early or late shifts. We do spirometry, phlebotomy, blood tests for a range of needs. We can refer patients direct to consultants which speeds things up a great deal." Community matron with specialist role in COPD.

The technical skills of the case manager could be a resource for others. The clinical nurse specialist in site one provided advice and input to the care of the patients of the community matron. There were also examples in site 2 and 3 where the community matron and clinical nurse specialist advised and reviewed the care provided by district nursing services in wound care, management of breathlessness and antibiotic prescribing. The care home case manager did not report providing any technical care but did provide support and advice to care home staff. This division of work had implications for how different nursing services worked together and is discussed further in the chapter.

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5.7.3 Palliative care

Eleven patients died during the period of data collection. End of life care was an area of care where the different focus of the nursing models was apparent.

District nurses in two sites saw care of the dying as a central part of their role and expected to provide this to their case managed patients. Approaching the end of life would often be the reason that the patient was identified as being in need of case management. In site 3, the district nurse would regularly meet with the Macmillan nurse services to maintain ongoing working relationship and to update their skills. The care home case manager saw helping older people and the care home staff develop advanced care plans as an important part of her role, as well as monitoring older people approaching the end of life so that she could involve palliative care services.

The community matrons stated that role in supporting people at the end of life was twofold: 1) as the co-ordinator of palliative care and 2) as an advocate for the patient. In three cases in two sites there were examples of the community matrons helping to communicate to others an older person's wishes and decision to refuse further interventions or treatment.

In contrast, the clinical nurse specialists described how they would involve palliative care services when patients were in the end stage of their disease (COPD and heart failure). One clinical nurse specialist commented that this was an increasing area of work that was difficult to resolve within a disease model of case management as, while they would want to refer patients to palliative care services, because of the patients' particular symptoms and medication needs it was not clear who should lead and manage the terminal phase of the illness. Patients' experiences of approaching the end of life are discussed in more detail in chapter 8.

5.7.4 Patient education

All the nurses reported that they provided patient education. Their reported aims were helping patients and carers to understand their disease and their medication regimes, to manage their symptoms and to improve their overall health. There were few examples from the nurses' interviews where they described particular health promotion goals or strategies to help patients change their behaviour. A small number of patients said that their case manager had helped them to stop smoking, or encouraged them to increase their daily activities or taught them strategies that reduced their anxiety about becoming breathless and using portable oxygen machines to enable them to get out of the house. Towards the end of data collection one of the clinical nurse specialists working with patients with heart failure considered that she could have a more significant role in disease prevention through health promotion activities in general practice and other disease-specific specialist services. In this she was signalling a desire to move away from the type patient education and self-management that was associated with the support of patients in the advanced stage of their disease.

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5.7.5 Carer support

In the patient interviews it was apparent that the involvement of a nurse case manager, particularly the community matrons, was often as significant a support for the family carer as for patients themselves. We asked the nurses about their involvement with family carers and whilst none saw their work as being primarily to support the carer, almost all recognised that often the carers had equivalent needs and were themselves in danger of becoming ill. One district nurse commented that it was "natural" to look after the carers and in site 3 the district nurse was undertaking a form of carers' assessments alongside patient assessments. Nurses said that they provided emotional support through "simply listening", signposting carers to services and coordinating assistance. There were several examples of where the case manager would actively seek services, such as additional social care, for the carer as well as the patient:

"He's had a bad time and his wife was struggling to cope. Case managing him means I can make sure she gets the help she needs too." District Nurse

Community matrons and district nurses appeared to have the greatest involvement in providing support to carers. For example, in one instance both a husband and wife had been identified as at risk of unplanned hospital admission. Who the carer and the patient became interchangeable:

"They care for each other, and both were found through the PARR tool, although a GP had referred them to me at about the same time. Both have complex needs and need both nursing care and help to care for each other" Community Matron

In other situations having a case manager was seen as the difference between a carer being able to continue in that role or not. In this example the case manager represents herself as being the "backup" and reassurance should the carer no longer be able to continue as the patient's actual case manager:

"I case manage him because his carer asked for an emergency action package to be put in place. He needs little direct care from us because she has everything extremely well worked out, including paid care, but we need to know what to do immediately, if his carer becomes unable to look after him." District Nurse

The different nurse case managers described their work with carers as focused on supplementing their caring work and helping them to continue in that role. One case manager did organise (see quote above) continuing care services for a patient to enable him to stay at home in the event that his carer die or no longer be able to look after him. It was an unusual example of anticipatory care that did not relieve the carer but did address her anxieties about what could happen in the future.

In contrast to the many examples of case managers improving access to services for their patients one district nurse observed that she had found it to be easier and quicker for carers to refer themselves to social services or

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the carers' centre if they needed more assistance, rather than going through her.

5.7.6 Maintaining continuity

Patients highlighted the disadvantages of receiving a service that was interrupted by holidays and nurses not being available outside of office hours (chapter 9). Across the three sites there were formal and informal methods of maintaining continuity of care. Case managers based within teams were more able to refer patients to colleagues when they were on annual or study leave. Two sites provided district nursing cover every day into the early evening (20.00H, 22.00H respectively) and by the end of data collection site two had commissioned over night cover from an external provider. The inner city site could provide 24hour district nursing cover. This out of hours service was not equivalent to case manager support.

Two of the clinical nurse specialists and the care home case manager had cover from their team when they were on annual leave, but could not offer out-of-hours support. Community matrons, before their work became more aligned with district nursing services, either could not provide cover when they were away or relied on ad hoc arrangements with colleagues:

"Officially I work alone not as part of the team. However in reality the six of us worked together quite closely and shared caseloads when one of us ill or away from work for some other reason". Community matron

For those working in the newer services, such as community matrons, there were more meetings and training commitments that directly affected their ability to maintain contact with patients. One community matron described how one week had been taken up with three days of training, two clinical supervision sessions, and a continuing care application. As there was no one to share the work with she described working on her day off and over the weekend to get the work done. This was compounded by having to provide cover for other nursing services:

"The other community matrons (CMs) are having the same problems. The CMs also have to give on call support for the district nursing team now so sometimes she has to see their patients as well as her own when she is on call, especially those needing palliative care". Community matron

Not all the case managers saw continuity of care between one case manager and a patient as important. A district nurse suggested that having different nurses visiting from the district nursing team meant that different issues were identified. The key worker role was shared. It was difficult not to see this arrangement as more likely to benefit the nursing staff than the patients being case managed.

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5.8 Working beyond the immediate team

The nurse case managers were working in a broader context with multiple other services in supporting their patients and carers.

5.8.1 Work with other primary care based nurses

The level of referral and overlap between community matrons, district nurses, clinical nurse specialists, and the nurse practitioner other nurses in the organisation (palliative care and district nursing) was an unexpected finding (see also section 8.6). These networks of referral appeared to be individually negotiated. When clinical nurse specialists were involved there was a suggestion the decision about who would be the 'lead' nurse or service for each patient was related to the level of input required:

"We work closely with other teams, depending on the needs of patients If leg ulcer is the primary diagnosis we often case manage a patient, however if they have multiple needs they are likely to be case managed by a community matron or district nurse who calls us in to do whatever they need us to do." Clinical nurse specialist

The work boundaries between district nurses and community matrons became increasingly blurred over the data collection period and in part reflected the organisations' lack of clarity about how the two services should work together. For some there was a suggestion that one service was more senior to the other, supported by the differences in pay band. There were examples of where the community matron would direct the care that the district nursing service should provide. This would involve daily care such as monitoring of vital signs and medication. Furthermore, many of the community matrons had a district nursing background and compared how the work they did now was more technically advanced and more patient-focused:

"I was finding the limitations of the district nursing frustrating. I found myself working informally as a case manager and like doing it that way, but couldn't really be effective within that as a district nurse. I applied for the job because I wanted a new challenge and this created that challenge." Community matron

The tensions of an implicit hierarchy were most apparent when, towards the end of the study, community matron services were being co-located with district nursing services. In site 1.there was an expectation that the community matrons would work closely with and give clinical support to the district nurses, and cover for each other's patients. The community matron described this as "horrendous" as she could only share a small part of her caseload because she doubted the expertise of the other nurses. Similar tensions were apparent in the other sites. This district nurse recognised that what the community matrons did was a different kind of care but was concerned about what she saw as the exclusivity of their work:

"Had a bit of an argument with the CM team here about who they should be caring for, and how they seem quite restrictive and if what they do is

effective, I think some of my patients could benefit from CM type care. I'm not against the CMs I just don't think they want to work with they seem to live in their own little world. To me it seems quite a luxury to have 20-30 patients and that is all you do." District nurse

Patients' experiences of receiving care from more than one community based nursing service are described in more detail in chapters 8 and 9.

5.8.2 Working with other health and social care services

The importance of having good working relationships with local authority adult social services, therapists, GPs and hospital services was a recurrent theme through all the interviews. At the final interview it was also used as one way of judging success, an indicator of how well known and integrated their work was with other services:

"As the service becomes better known and trusted we are getting more referrals from care homes." Care home nurse case manager

As one of the newest services community matrons saw this as one of their most significant achievements, at the end of the data collection period:

"I feel more established in the job and if we as a team are respected in this part of the world which makes our work far better and easier." Community matron

This community matron described how she had worked hard at developing relationships with the COPD and CHD services, by arranging meetings with them, and how she was beginning to receive some referrals from them. Nevertheless, referrals to specialist services still had to be mediated through the GP, and this depended on the value and expertise of the community matron being recognised by others:

"One of my patients has improved and that is excellent. She had an angioplasty following my referral of her to her GP, and his referral onto a heart specialist, and that's helped her a lot. I feel that this patient may have helped the GP to see that I can do a professional job and he's been a bit more accepting of me the past few days. He even made me a cup of tea and bought it into my office, which is unheard of." Community Matron

One of the consequences for case managers (CM and CNS) of having to negotiate their relationships with other services and "earn recognition" as the patients' key worker was that, from an organisational perspective, there was no clarity about who was responsible for he patient's care or for communicating information to the patient or to other professionals. There were examples of blood test results requested by the clinical nurse specialist being sent to the GP and social care services being organised by hospital staff for a patient without reference to or communication with their community matron.

District nurses across the three sites had a small but established network that included GPs, social workers and therapists that they met regularly with to discuss particular patients. This case manager model was the most embedded in the organisation but arguably had the least recognition or

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mandate to develop the role. This was because of their larger caseloads and training and managerial responsibilities as leaders of skill mixed nursing teams.

5.9 Organisational change and review

All three sites experienced organisational review and change over the nine months of the case study phase (table 22 chapter 4). Some of these were reviews of all the services but community matrons experienced the most changes and challenges to their role. All the sites had commissioned reviews of their community nursing services either just before or during the study. In site 1, the community matrons were realigned with the DN team and this changed the nurses they worked with and how they were managed. In Site 2 the community matrons were already working from GP surgeries, which allowed for close liaison with DNs but there were plans for the community matrons' service to be absorbed fully back into DN teams.

Monthly interviews with the nurses highlighted how disruptive the practitioners found these changes and their feeling that there was never enough time to embed the service within the organisation or to learn from the changes. Others talked of their low morale, the distance they felt from their managers and the difficulties of maintaining relationships with other services. Two months after this interview the district nurse had left to work in another PCT:

I'm peeved with the Trust, they seem determined to devalue us and make our work as hard as they can. Now we have yet another review to review the changes made after the last review. They don't even give us time to settle before they are assessing us again." District nurse

Other nurses were more reconciled to change and whilst they acknowledged it had a negative effect on how they worked they accepted this was an inevitable part of their work. The community matron quoted below is from the same PCT as the district nurse quoted above:

"There is talk of district nurses doing 50% case management. Now that GPs are moving to practice-based commissioning some of them would like community matrons to going to the surgeries and set up there so that they can share responsibilities over to the community matrons. That's not our philosophy and it feels wrong. I guess I'm just being prepared for any eventuality in the future because I think a lot will change. Whatever happens we just have to go with it and make it work, but it's frustrating because it means we can never settle down to do what we want to do. There's talk of us having to move back to within the district nursing team, we really don't want to do that." Community matron

One clinical nurse specialist moved posts during the study and the study's final interview with her occurred after she had taken up her new role. In her view, developing a post or retaining its core activities was difficult when there was surrounding organisational turbulence:

"The trouble is that because of all the change there you can never properly see something through to completing, whether your responsibility is small or large. And if they think you are good they load stuff on you until you just can't cope any more, which as you know is what happened with me."
Clinical nurse specialist

She also highlighted that those practitioners who the organisation recognised as "good" were likely to be moved on to do other work and not stay in front line nursing.

Although all the services in the three sites were subject to reorganisation, the nurse case managers, and particularly the community matrons were most susceptible to change. It reflected an organisational view of nurse case management as malleable and interchangeable with other nursing services.

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6 The patient characteristics

6.1 Introduction

This chapter presents the description of the patient sample, compares the case mix of the different types of nurse case managers, considers the patient use of services and concludes with a description of their health experiences over the nine months of the study. It presents data that contributes to answering the case study questions of:

- What is the impact of nurses' contribution to the experiences of patients and carers?
- What are the factors that enable nurse case managers to contribute most effectively to successful outcomes of care?
- What is the impact of the nurse case manager's contribution upon the cost, quality, effectiveness, and organisation of the care provided?
- What are the factors that sustain the models of nurse case management over time?

6.2 The sample of patients

The original aim of this study was to recruit the last 5 older people who had been admitted to a case manager's caseload, and who had been on the caseload for no more than 1 year and ideally for 3 months or less. The inclusion criteria for the study (being over 60, expected to live for 9 months, having no severe dementia or mental health problems) posed some challenges when recruiting the sample. The Specialist Nurses found it difficult to identify suitable patients aged over 60 years. Community Matrons were not always able to identify patients expected to survive for 9 months, while district nurses were constrained both by the age and frailty of their patients and the numbers who they could identify as being case managed:

"It's difficult to find enough patients to fit with your criteria, quite a few of mine tend to be either younger, or if they are older they are too ill, or deteriorating quite quickly". District Nurse

There was also some 'gate keeping' by the nurses based on their professional values and their experiences. Some would not approach certain patients about the study if they felt the patient was emotionally or otherwise too fragile to take part or if they were concerned that participation in the study would damage a nurse/patient relationship that was still in its early stages:

"I have a couple of patients that are new to me, but I am still assessing them and I don't think it's the right time to ask them about a study. Both of them are probably too ill anyhow. I wouldn't want to ask any of my patients

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that I think might be worried to say no but not really want to do it –some of them have had a hard time and are quite nervous and frail, sometimes it is was enough for them to accept me into their lives and they have had a lot of contact from all kinds of people as a result. I think the study would be too much for them." Community Matron

Patients new to a case manager's caseload often were in the process of encountering a number of other practitioners from a variety of agencies. Consequently, on a few occasions nurses identified eligible patients but asked that we delay making contact with them so that new faces did not overwhelm them. Another also acknowledged her protectiveness of patients:

"I am very protective of my patients, and there are some it would not be right to ask because they are too frail, or because I am still building their trust in me". District nurse

Following these filters, 89 patients were approached but of these 12 felt too ill to take part, 9 were not interested in taking part, 9 felt they did not have time and the remaining three gave no reason for declining (Table 30). Those with insufficient time to take part were primarily patients of specialist nursing services, or those with caring responsibilities.

Table 30. Reasons for not taking part

	Lack of time	Health	Not interested	Not relevant	None given	Total
Patients	9	12	9		3	33
Carers	2		1	3		6

Following an extended process of recruitment 56 patients agreed to participate in the study. Of the sample of 56, 5 people either died (4) or became too ill (1) to participate during the first month of the study. This meant that 51 patients were participating in the study at baseline (see table 31)

Table 31. Patient and carer recruitment to the sample

	Approached	Consented	Withdrawn/RIP within first month	Remaining at baseline
Patients	89	56	5	51
Carers	15	9	2	7

All of those taking part lived within the PCT area of their respective nurses at the start of the study. One moved to an adjacent area in the course of the nine months, remaining on her nurse's specialist caseload because there was not an equivalent service in the area. Two patients did not feel well enough to be interviewed during the study but gave permission for their

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care to be tracked using nursing notes and interviews at the beginning and end of the data collection.

6.2.1 Joining a nurse case manager's caseload

The study aimed to recruit patients as close to the commencement of having a nurse case manager as possible. The samples time on the nurse case managers' caseload ranged from 1- 22 months. The length of time reflecting the recruitment issues outlined above. The mean time on caseload prior to the study for all patients was 3 months (table 32). The range for Community Matrons was higher than that of other nurses, primarily because the Community Matron in one site had a well-established caseload and had not taken on many eligible new patients in the months prior to the commencement of the study. Patients who had been on a nurse case manager's caseload for several months prior to joining the study had an established relationship with their case manager. It might be expected that less change is seen among patients who have been on nurses' caseloads for the longest periods.

Table 32. Time on nurses caseload prior to joining study

	Nurse case manager type					
Time on case load prior to joining (months)	CM (n=21)	DN (n=11)	CNS (n=13)	CHST (n=3)	NP (n=3)	All types
Mean	4.5	1.5	3	1.7	1.7	3.4
Median	3	1	3	2	2	2
Mode	1	1	1	-	-	2
Range	1-22	1-6	1-6	1-2	1-2	1-22
Standard Deviation	5.09	1.37	1.95	0.58	0.58	3.57

Key: CM = Community Matron, DN= District Nurse, CNS=Community Nurse Specialist, PN=Practice Nurse, CHST = Care Home support team

Patients were referred to a nurse case manager in a variety of ways; following an admission to hospital or through a medical consultant, from a GP, as a patient of an existing community nursing service or through a process of case finding (table 33).

Referral between nursing services occurred when patients, because of the increasing complexity of their condition or situation, were judged to need more structured assessment and support than they were currently receiving. It was interesting that many of the community matrons' patients were referred to them by other community nursing services (typically specialist nursing services). Among district nurses who had a case manager component to their work, there was a relatively high level of referral from the wider district nursing team (54%).

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Table 33. Referral routes to nurse case managers

Referral route to nurse case manager	Nurse case manager type					
	CM (n=21)	DN (n=11)	CNS (n=13)	CHST (n=3)	NP (n=3)	All types
GP referral Hospital referral	5 (24%)	5(45%)	2 (15%)			*12 (23%)*
Referral from hospital	5(24%)	1 (10%)	6(47 %)			*12 (23%)*
Referral from within the same community nurse/DN service		5(45%)	4 (30 %)			*9(18%)*
Referral from another community nurse/DN service	3 (14%)		1(8%)			*4 (8%)*
Referral from care home				3 (100%)		*3 (6%)*
Case finding	8 (38%)					*8 (16%)*
Identified from GP records					3 (100%)	*3 (6%)*

Community Nurse Specialists received over half of their patients through secondary care referral. Referrals made from secondary care were frequently made after an exacerbation leading to hospital admission where the hospital team or specialist considered that intensive support would be needed when the patient returned home. Patients were usually appreciative of this, especially if they had had negative experiences of discharge in the past:

"It made a difference. Before when I came out they sent in a nurse for a few days and it was, well, kind of, nothing. You know? This time it was better, she came to see me almost as soon as I got home and she seems to have been around ever since, and she seems to have helped sort out things I need". Community Matron Patient

"The consultant told me about the COPD nurses and said that he thought they would help me. He told me about the rehab course and said he'd suggest they put me on it. That's all I was expecting really, but they have been much more helpful than that. They look after everything, and even helped me with my heart problems and my problems with my GP". Nurse specialist Patient

Of the 51 patients in the sample, 9 were taken on to a nurse case management system through active case finding (usually using the Patient At Risk of Readmission PARR tool). Of these, 8 were the patients of Community Matrons. One nurse specialist used the PARR tool to review cases within her team's caseload. Patients identified by case finding were

'high intensity' users who had had 3 or more chronic or long-term conditions and a minimum of 3 unplanned hospital admissions in the year prior to their identification.

Patients admitted to caseloads often expressed surprise at finding they had been allocated a Community Matron. As 'high intensity' service users they tended to be familiar with chains of referral and referral processes. Being approached independently, without a GP or other professional telling them this would be happening, initially worried some patients:

"I don't really know where she came from. She just phones out of the blue one day, nobody told me she would be getting in touch, and usually that's what they do. I don't know someone like the doctor or the heart man tells you they will be putting you in touch with someone. But this time she just appeared." Community Matron Patient

"I don't really know how she found out about me, and at first I was worried about that. I thought maybe they wanted to put me in a home or something because she came and asked all these questions and spent so long with me. Most of them don't do that, do they?" Community Matron Patient

During the course of the study there was a shift in how patients were identified for case managed support and community matrons started to take more referrals from GPs and hospital consultants. The PARR tool was not identifying new patients for their caseloads and using a structured model of this type missed some patients with high intensity needs who had not been admitted to hospital.

6.3 The patients' demographic profile

In total, 51 patients were recruited across the three study sites of which 21 were male and 30 female (table 34). Their ages ranged from 64 to 98 years old with a mean age of 77 years (st dev 9, median 75). The majority of the patients' ethnicity was white and almost all had English as their first language. Over half of them lived with others, 26 (51%), but 22 (43%) lived alone, and 3 (6%) lived in a care home. Only 13 (25%) of the older people had a family carer, although a further 14 were receiving some form of unpaid support in their daily lives from friends and family, and 20% (10 51) received social care support, typically a home care worker. The majority of them were homeowners, 33 (65%), and just under a third of the sample was renting accommodation, 15 (29%). The demographics of the sample differed slightly by site, but were broadly typical of the demographic profile of the area in which they were based, as described in chapter 4.

Table 34. Patients' demographic profile by study site

Characteristic	Site 1 (n=15)	Site 2(n=20)	Site 3(n=16)
Male	4(27%)	11(55%)	6(38%)
Female	11(73%)	9 (45%)	10(62%)
Age Range	65-91	64-94	68-98
Live alone	9(60%)	10(50%)	3(19%)
Live with another	6 (40%)	7 (35%)	10(62%)
Has a family carer	3 (20%)	6(30%)	4(25%)
Has a paid care worker	3 (20%)	4 (20%)	3 (19%)
Receiving disability benefits	10(67%)	16(80%)	11(69%)
Accommodation type	Owned 5 (33%) Rented 10 (67%)	Owned 16 (80%) Rented 4 (20%)	Owned 12 (75%) Rented 1(6%) Care home 3 (19%)

Approximately the same numbers of patients were recruited in each site. Site 2 had more men than women, 11 (55%), but sites 1 and 3 were similar in their proportions of each gender. There was little difference in the age ranges across the 3 sites. A higher proportion of older people were living alone in site 1 and the highest proportion of older people who were living with others was in site 3, 10 (62%). Older people in site 2 had the highest proportion of family carers, 6 (30%); sites 1 and 3 had similar proportions of older people with family carers. There was no variability across the sites in terms of the proportion of older people who received help from a home care worker. The highest proportion of older people receiving disability benefits was in site 2, 16 out of 20 (80%), with sites 1 and 3 having approximately the same proportions at 67% and 69%. There were marked differences in accommodation type when comparing site 1 with 2 and 3. In sites 2 and 3 the majority of the older people were homeowners, in contrast to site 1 where the majority rented their accommodation. This reflects with the socio-demographic profile of each case study area (see chapter 4).

6.3.1 Demographic and socio economic profile by nurse model

Only small numbers of older people were recruited through the Nurse Practitioner and Care Home Nurse Specialist (table 35) and the following comparisons, therefore, focus on the community matrons, district nurses and nurse specialists. The community matrons and district nurses were case managing the oldest patients. Over half of the older people being case managed by the community matron and district nurses were living alone:

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12 (57%) and 6 (55%) respectively, compared with just under half of the nurse specialists' patients: 6 (46%).

Table 35. Patient characteristics by type of nurse case manager

	Nurse case manager type				
Characteristic	CM (n=21)	DN (n=11)	CNS (n=13)	PN (n=3)	CHST (n=3)
Male	10	4	6	0	1
Female	11	7	7	3	2
Age Range	68-91	65-88	64-79	77-89	86-98
Live alone	12(57%)	6(55%)	6(46%)	1	n/a
Has a family carer	6(29%)	5(45%)	1(8%)	1	n/k
Has a paid care worker	6 (29%)	3(27%)	0	2	n/a
Receiving disability benefits	20(95%)	9(82%)	8(62%)	1	1
Accommodation type	Owned 14 (67%) Rented 7 (33%)	Owned 8 (73%) Rented 3 (27%)	Owned 10 (77%) Rented 3 (23%)	Owned 1 Rented 2	Care Home 3

Older people being case managed by the district nurses had the highest proportion of family carers, 5 (45%). Similar proportions of older people case managed by district nurses and community matrons received support from a home care worker, 27% and 29% respectively. None of the older people being case managed by a nurse specialist had a family carer and only one had an home care worker, reflecting their relative independence, they also received fewer disability benefits than the other two groups; 8 out of 13 (62%), with the community matron patients being the most likely to be in receipt of disability benefits, 20 out of 21 (95%).

6.3.2 Family carers

11 carers were invited to take part in the study and 9 of these consented to take part (table 36). One carer declined because he was not interested; three declined because they did not have time. Of the 9 carers who agreed to take part, 8 were the spouses living with patients and 1 was another family member who lived 3 days a week with the patient and the rest of her time in her own home. Eight other patients had partners who lived with them but who were not recruited to the study as a carer because the partner was not recognised by the case manager as undertaking significant caring role. 5 of these were the partners of patients of the specialist nurses.

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Table 36. Family Carer Characteristics

Characteristic	Number (n=7)
Male	1
Female	6
Resident with participant full time	6
Resident with participant part time	1
Minor health problems	3
Serious health problems	3

A further eight patients had family members living close by who were providing a support or care in some ways, such as doing shopping and checking on the patient, or talking with Case Managers about the patient's care. However the patient in each of these cases did not consider their supportive family to be carers. Where possible, and with the assent of the patient, these family members were contacted, but most of the people who declined to take part were in this group, giving their reasons for refusal as lack of time or lack of identification with a carer role (table 37).

Typically, patients were very clear that their partner was not their carer and that they had no need for care from this source:

"No, I get on fine. I don't need him to look after me at all. My legs are a nuisance but I still do everything for myself and don't need more than I did before. The main thing is that sometimes he needs to drive more than he used to because when my legs are bad I can't drive for long." Community matron patient

In one case a patient's husband was officially named as and was receiving benefits as a carer for his wife, because of her apparent need to have someone with her 24 hours a day due to her heart problems and mobility problems; however he did not feel he had a caring role for the purposes of the study. This carer declined to take part because:

"I really don't do much; I'm just named and paid benefit as the person who's around to make sure she's OK. You know I'm not her carer really, except for driving her places: she does most of the caring for me, so you'll have to ask her everything anyway." Carer for patient

People living in care homes were atypical of the sample as a whole because they were by definition receiving paid care. However, in one case the family members were still important to the health and well being of the patient, visiting regularly with the patient and liaising with care home staff about the patient's progress and need. In another case the patient lived in the same care home as her brother, and this was important to both individuals.

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Table 37. Availability of carer support to patients

Availability and type of carers	Nurse case manager type					
	CM (n=21)	DN (n=11)	CNS (n=13)	PN (n=3)	CHST (n=3)	All types
None	13 (60%)	3(27%)	9 (69%)	0	1 (33%)	26
Family	3(14%)	3(27%)	1 (8%)	0	1 (33%)	8
Paid	3(14%)	3(27%)	3 (23%)	0	1 (33%)	10
Both	2 (15%)	2(18%)	0	0	0	4
Resident of care home				3(100%)		3

6.3.3 Social inclusion and networking

We were interested to know if people receiving case management were socially isolated and needed nursing to compensate for the adverse consequences of this. Participants were asked in general terms about their social networks, how they interacted with them, and what support these networks provided in terms of their health and social needs. They were asked: who was significant in their lives, who they saw or heard from at least once a month, who they could confide in and who was providing support which helped with their health problems or daily life. These questions were drawn from the Lubbens Social Network Scale (Lubben et al 2006) although this was not used as a formal validated tool in the data collection. The data collected in the informal questions about social networks asked about, relations, friends, and others who were important to the patient but who were not their main carer.

The data from these questions were analysed to capture whether patients had an identifiable social network at baseline that could be described as either providing informal support for the patient's health or social care, or solely as a source of social support. Table 38 summarises the social and support networks of the patient participants, by nurse model.

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Table 38. Patient social and support networks

Social Network Types	Nurse case manager type					
	CM (n=21)	DN (n=11)	CNS (n=13)	PN (n=3)	CHST (n=3)	All types
None	3 (14%)					3(6%)
Social only	5(24%)	4 (27%)	9 (69%)	5 (83%)	23(45%)	
Social and informally supportive	13 (62%)	7	4(31%)	1 (17%)	25(49%)	

Patients of Community Matrons were more likely to be socially isolated and unsupported than patients of other nurses in the study. However, for two of these patients with no social network, it appeared that this was by personal choice: they did not want to have a social network around them, or to have informal health and social care support. Indeed, one of these patients only accepted nursing help because it facilitated her in staying in her own home. Another patient felt that she was coming to the end of her life:

"I've had my time, I am content enough. I don't want all that fuss. If my body is getting tired and my time is coming I just want to let it be, why should I have all these people fussing and fiddling around me when I am content to be as I am?" Patient

The majority of patients of specialist nurses saw themselves as independent, reflecting the lower health and social needs of this group of patients:

"I have plenty of friends and my family are all around here so it's good. But no. No, they don't do anything for me like helping out with things". Nurse specialist patient

The patients of the District Nurse patients were more likely to have informal supportive networks than others. Among Community Matron patients slightly less than half had a supportive network they could identify, and for these patients their social isolation was an explicit contributing factor in their admission to the case management service.

6.4 Patients' health status and dependency levels

The Barthel scale was used both at baseline and after nine months to measure the patients' level of functional ability. (Mahoney and Barthel 1965). This asks questions about levels of patient dependency in ten measures of continence and personal care, ability to transfer and mobility – the degree to which patients are independent in these or need help from other people. The scores are then converted into a simplified scale of dependency with five levels – Total (the patient is completely dependent

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upon others for all aspects of living) through Severe, Moderate, Low to Very Low (The patient is independent in all aspects of personal care and mobility).

6.4.1 Dependency levels

Excluding care home patients, levels of dependency among patients were similar for all case management models (table 39). Two thirds of the sample had very low levels of dependency and a further quarter had a low level of dependency and this was similar for all nurse case management models, with District Nurse patients having slightly higher levels of dependency than Community Matrons. The people with highest levels of dependency were usually living in care homes or sheltered housing.

Table 39. Level of dependency on others of patients

Dependency level (Barthel Scale)	Patients' nurse case manager type					
	CM (n=21)	DN (n=11)	CNS (n=13)	CHST (n=3)	NP (n=3)	All
Very low	14 (67%)	4 (40%)	12 (92%)		1	31
Low	6 (28%)	4(40%)	1 (8%)			11
Moderate	1 (5%)	2(20%)		1(67%)		4
Severe		1 (10%)		2 (33%)		2
Not Known					2	2
TOTAL no. Patients	21	11	13	3	3	51

Patients of nurse specialists generally were more independent than the rest of the sample. Only one patient in the sample was totally dependent, a person with quadriplegia whose wife was his main carer. This person had been a patient of a District Nurse who had been bought into the Case Management caseload when the patient's wife requested an emergency care package be put in place to provide a package of care should she be taken ill or otherwise be unable to care. In this case the couple lived in their own in a specially adapted flat with many hours of home care support for which they paid. Although the patient's dependency levels were severe and his care needs intensive he only infrequently contacted his GP and rarely visited a consultant or experienced a hospital admission. His wife was his case manager, co-ordinating the different services he received and anticipating future needs.

6.4.2 Cognitive impairment

Although the study inclusion criteria excluded patients with enduring mental health problems it was expected that, because of age, some patients would have a degree of cognitive impairment. This was assessed using a standardised tool: the Kingshill version of the six-item cognitive impairment test (Brooke and Bullock 1999). The cognitive status of patients was measured at baseline. A difference can be seen in the cognitive impairment levels of patients across the case management models. Two thirds of all study patients (including all the clinical nurse specialist patients) had no cognitive impairment but of the few (n=9) that did have impairment the majority were community matron patients (see *table 40*).

Table 40. Cognitive impairment at baseline of participants

Cognitive impairment level (measured by CIT score)	Patients' nurse case manager type					
	CM (n=21)	DN (n=11)	CNS (n=13)	CHST (n=3)	NP (n=3)	All patients (n=51)
None	12 (57%)	8 (72%)	13 (100%)		3 (100%)	*36* (71%)
Moderate	8 (38%)	2 (20%)		2 (67%)		*12 (24%)*
High	1 (5%)	1(10%)		1 (33%)		*3* (5%)

6.4.3 Health conditions and co-morbidities

The sample in this study had a broad range of health conditions clustered around prevalent conditions of Chronic Obstructive Pulmonary Disease (COPD), Chronic Heart Disease (CHD), Diabetes, Cerebral-vascular Accident (CVA). The health of this sample is consistent with the health characteristics that would be expected from the literature on the patients supported by Nurse Case Management (see chapter 2) and reflects, in part, the disease focus of the clinical nurse specialist participants.

6.4.4 Health conditions by model of nurse case manager

The co-morbidities of the patients in this study reflected the illness profiles of the patients of each nurse case manager type. The sample size is too small to be considered statistically representative but it includes patients with the range and types of conditions experienced by people in this population group.

Table 41 reveals little difference between the numbers of conditions suffered by patients in all 5 case management models. The patients of Community Matrons were slightly more likely to have 3 or more conditions reflecting the process of admission to the caseload.

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Nurse Specialist patients had fewer co-morbidities than patients of other models (7 (54%) had 0-2 conditions compared to 2 (18%) for district nurses, 3 (14%)for community matrons and none for other models). Over half of these patients also had one or more conditions related to their primary condition. The nature of the co-morbidities of the patients of nurse specialists and their lower age range reflects the pattern of illness and age profile of the nurse specialists' caseloads. These patients tend to be younger than those in other case manager models and to have lower levels of health and social isolation.

Table 41. Number of health conditions per patient

Number of health conditions	Patients' nurse case management type					
	CM	DN	CNS	CHST	NP	All
0-2	3 (14%)	2 (18%)	7 (54%)			12 (24%)
3-5	18 (85%)	8 (71%)	6 (46%)	3 (100%)	3(100%)	38 (74%)
6+		1(1%)				1 (2%)
Mean	3.4	3.8	2.6	3.7	4	3.3
Median	3	4	2	4	4	3
Mode	3	3.5	2	4	3.4.5	3
Range	1-5	2-6	2-4	3-4	3-5	1-6
TOTAL no. Patients	21	11	13	3	3	51

6.4.5 Types of conditions experienced by patients

We defined the primary condition as that which the patient identified as their main health problem. Where this was not certain, the condition for which the case managing nurse was mainly providing care (in the case of nurse specialists) or the condition reported as having the greatest impact on the patient's life, was used.

Among the 51 patients recruited to the study there were 11 different primary conditions, with 5 of these accounting for over 70% of the sample. For 13 (25%) COPD was the main condition, 8(16%) had CHD as their main condition, 7 (14%) had leg ulcers and 8(6%) had diabetes. The focus of the clinical nurse specialists directly influenced the presence of patients with CHD and leg ulcers and to a lesser extent in COPD; however, all three of these conditions were experienced by patients across all 3 main nursing models. The most common combinations of chronic disease were COPD and CHD. Community Matrons and District Nurse case managers were treating patients who had a wider range of conditions than the Clinical Nurse Specialists (table 42).

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Table 42. Prevalence of conditions experienced by participants

Main health conditions	Patients' nurse case management type					
	CM	DN	CNS	CHST	NP	All
COPD	12	2	3	1		13
CHD	1	1	6	1		8
Leg Ulcer	1	2	4			7
Diabetes	3	3				4
CVA	3	1				3
Rheumatoid Arthritis		1				1
Kidney Disease	1					1
Dementia		1				1
Arthritis				1		1
Osteoarthritis					2	2
Macular degeneration					1	1
TOTAL no. Patients	21	11	13	3	3	51

6.4.6 Depression

The 4 question Geriatric Depression scale was used to help assess patients' levels of depression (Sheikh, and Yesavage 1986). A score of 0 indicates no depression and 4 indicate a high level of depression. Not all patients responded to this question, but of those that did half (17) reported no symptoms of depression, and this was consistent across all models. Of those with symptoms of depression the majority reported a low level of depression; only 5 people out of the 34 that responded scored 4 on the scale. However, 12 patients in the sample were taking antidepressants, the majority of which had low or no symptoms of depression and 2 patients scored 3 or 4 respectively on the scale. The proportion of patients taking antidepressants is consistent across the case management models, although slightly lower for Nurse Specialist patients and fits with this group's higher level of independence and self efficacy than with the other two models (table 43).

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Table 43. Symptoms of depression in patients

Symptoms of depression (GDS score1=low,4=high)	Patients' nurse case management type			
	CM	DN	CNS	Total
None	8(47%)	4(57%)	5(50%)	17(50%)
Mean	1.9	1.7	2.1	2.4
Median	1	1	1.5	1
Mode	1	1	1	1
Range	1-4	1-3	1-4	1-4
TOTAL no. Patients responding	17	7	10	34
Number of patients taking prescribed anti depressants (n=51)	6(29%)	3(28%)	3(23%)	12(24%)

6.4.7 Medication

The Community Matron patients had an average of 9.5 prescribed medications, compared to the study mean of 6.5 medications. District Nurses, Nurse Specialists and Care Home Case managers' patients had a range of 6.2 - 6.8 medications f. The Nurse practitioner patients had a mean of 8.7 medications (table 44). Where patients had high levels of prescribed medications (7 or more) it was common that not all medications were being used – some remained on the repeat prescription list despite being removed from active use for the patient. At least one quarter (13) of patients had one or more prescribed medication that they reported they did not take. Patients' decisions not to take medication were because they did not like the drug side effects, or because they weighed up the relative benefit of taking it compared to how they felt, and whether they considered it necessary. Typically this included diuretics and blood pressure medication.

The need for medication review was a key function of case managing nurses. Among people with three or more co-morbidities, or where 7 or more medications were being prescribed, qualitative evidence at baseline indicated that for over half of patients the nurse case managers were actively reviewing their medication. Depending on the level of qualification as a nurse prescriber, clinical nurse specialists and community matrons would then alter medication independently, or refer the patient to their GPs

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Table 44. Number of prescribed medications

Number of prescribed medications	Patients' nurse case management type					
	CM	DN	CNS	CHST	NP	Total
0-3		1 (10%)	3 (23%)			4 (8%)
3-6	5 (24%)	5 (40%)	5 (38%)	2 (67%)	1 (33%)	18 (35%)
7-10	10 (48%)	3(30%)	3 (23%)	1 (33%)	1 (33%)	18 (35%)
11+	6 (28%)	2 (20%)	2 (15%)		1 (33%)	11 (22%)
Mean	9.5	6.8	6.2	6.3	8.7	6.5
Median	8.5	5	4.5	4	9.7	5
Mode	8	3.5	4	4.6.9	5.8.16	4
Range	4-16	2-16	2-11	4-9	5-16	2-16
TOTAL no. Patients	21	11	13	3	3	51

6.4.8 Patient understanding and experience of their health problems

Self efficacy and a sense of lost personal control and power in poor health were of great significance to patients:

"Since my heart got bad and they found this atrial fibrillation they say is there it's like I have lost something, it's like I never know what might happen. And then there's the doctors and the clinics and all those tests – they take over your life. Oh and the tiredness, oh yes, the tiredness. It stops you functioning and I hate that". District Nurse patient

The Stanford Scale for self efficacy was used (Lorig et al 1989) to measure how well people were dealing with the symptoms of their health problems and the effects of their problems on their lives (see table 45).

A common feature of those newest to case management among the sample was their sense of uncertainly and lack of control of their chronic illness. This was a major concern for many patients:

"I know I'm ill, and I know it isn't going to go away. It's the uncertainty I hate. The always wondering when my breathing will suddenly go, just like that and then I collapse or just can't move. It's awful, hard to explain, just awful". Community Matron Patient

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Table 45. Patients self efficacy scores at baseline

Patients self efficacy scores (Stanford self efficacy scores 0=low,100=high)	Patients' nurse case management type			
	CM	DN	CNS	Total
Mean	42	41.5	42.5	*44.4*
Median	43.5	43.5	42.5	*43*
Mode	43	50	39	*43*
Range	22-55	21-50	20-57	*20-57*
TOTAL no. Patients responding	16	6	12	34

Note: CHST and NP not included as the sample was too small

Some patients had reached a point of acceptance that their illness would not get better and they would eventually die as a result – usually of the condition that they identified as being their main problem:

"It's all over really, isn't it? The best I can expect now is to get worse slowly and deal with it as best I can." District Nurse Patient

Others accepted the severity of their problems but were determined to live life fully, no matter what:

"So, I can't walk at the moment. Who cares? I will and that's what matters. I'm not going to let all of this stuff get me down, no way. I have escaped my old bad life now so I am going to do all I can to make this new life good, sod the illnesses, why should they get in my way?" District Nurse Patient

6.5 Use of services other than nurse case managers

It was difficult to assess at which stage of the long term condition trajectory the person was at when they were admitted to the nurse case manager's caseload. As demonstrated above many of the patients on the district nurse and clinical nurse specialist caseloads did not have as complex needs as those being cared for by the community matron. Nevertheless, there were patients of equivalent vulnerability in all the

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Table 46. Types of services used by the patients by types of nurse case managers at baseline

Services	Types of nurse case managers		
Primary Care	CM	CNS	DN
GP	√	√	√
District nurse	√	√	√
Community Pharmacist	√	√	√
Tissue viability nurse specialist	√	√	√
Dentist			√
Practice nurse		√	
Respiratory Community Matron	√		
Physiotherapist	√	√	√
Podiatrist	√	√	
Secondary Care Sector : Outpatients clinics	CM	CNS	DN
Ophthalmology	√		√
Rheumatology	√	√	
Orthopaedics	√	√	
Psychiatrist	√		
Cardiac	√	√	√
Geriatrician	√		√
Diabetic	√	√	√
Renal	√	√	√
Respiratory	√	√	
Warfarin clinic		√	
Local Authority, voluntary sector and other services	CM	CNS	DN
Home care worker (personal care)	√		√
Social worker/care manager	√		
Shopping service		√	
Meals on wheels	√		
Day centre	√		√
Domiciliary library service		√	
Occupational therapist			√
Sensory unit service		√	
Telephone support service (telecare)	√	√	√
Private Sector	CM	CNS	DN
Home care worker (personal care)	√		
Domestic help	√	√	

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caseloads and the majority were experienced users of health and or social care services.

At baseline the 51 patients in the total sample were using a total of 29 services from across the primary care, secondary, local authority, voluntary and private sectors (See table 46). A comparison of the patients with one of the 3 main types of case manager (community matrons [CMs] , community nurse specialists (CNS) or district nurse case managers (DNs)) showed that patients of the CMs and CNS were using approximately the same range of services; 22 and 19 respectively out of a possible 29 recorded. In comparison patients of the district nurse case manager were using only 14 types of other services.

6.5.1 Comparison of patient use of services by nurse case manager type

Although a total of 29 services were identified as being used, individual patients received between 2 and 15 services; with an average of 5 (median 4 St. dev 2) (see table 47) across all nurse case management types. The patients of the Nurse practitioner (NP) and the care home support team used the smallest range of services. There was little difference in the mean number of services received across the three main nurse case management models (CM, CNS, DN) at baseline.

Table 47. Number of services received at baseline

Patients receiving nurse case management	Range of Services received	Mean Number of services	Median Number of services
Those with CMs (n=21)	2 to 9	5	5 (St.dev 2)
Those with CNS (n=13)	2 to 15	5	4 (St.dev 3)
Those with DN team leader (n=11)	2 to 8	4	3 (St.dev 2)
Those with Care home support team (n=3)	2 to 3	2	
Those with Nurse practitioner(n=3)	2 to 5	4	
All patients (n=51)	2 to 15	5	4 (St.dev 2)

The information obtained through monthly telephone interviews with patients meant that it was possible to track any changes in service use over the nine months of their participation. Out of the 51 patients recruited at baseline, 30 (59%) who were case managed by the main models, completed all nine months of the study. Their service use during this time was analysed. The highest proportion of patients using additional services over the nine months were case managed by the nurse specialists (79%), followed by community matron and district nurse patients at 50% and 29% respectively (see table 48).

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Table 48. Additional services received by patients completing 9 months of the study

Type of case manager	Patients completing 9 months (n=30)	Number in receipt of additional services in 9 months	Range and mean additional services
CM	14 (67%)	7/14 (50%)	Range 1-5 Mean 3
CNS	9(69%)	7/9 (79%)	Range 1-3 Mean 2
DN	7(64%)	2/7 (29%)	Range 1 Mean 1
Totals	30 out of51 (59%)	16/30 (53%)	Range 1-5 Mean 2

All referrals and requests for these additional services for CNS and DN patients were made by the GP or the patient themselves. In contrast, the CMs made 13 out of the 17 additional different service referrals (76%) for their patients (see table 49). In line with the baseline data, the community matron patients also received the widest range of additional services over the nine months compared with the other two models.

This may be a result of differing role perception between the nurse case managers. For example, community matrons may have seen service referral as a large part of their role. Service use at baseline will also have been affected by the length of time which the patients had been on the nurse case manager's caseload when they were first referred to the study. This varied between a few weeks to as long as 22 months. Another important factor to take into account is that patients with long term conditions are on a downward trajectory in terms of their health. Consequently, as their condition deteriorates, they become less independent and require more help with complex and interrelated conditions and symptom control, so the likelihood of increased referrals to more services rises.

Table 49. Types of additional service use over 9 months by model and referrer

Patient received type of case manager	Type of service referred to by professional or self requested	Type of service referred to by nurse case manager	Number of case manager referrals
CM	Cardiac outpatients (GP), cardiac exercise group (secondary care), practice nurse (GP),	Community centre, hospice, palliative care team, cardiac nurse specialist, phlebotomist, physiotherapist, occupational therapist, social services for a home care worker, social worker.	13/17 (76%)
CNS	Private dietician (patient), warfarin clinic (secondary care), counsellor (GP), physiotherapist (GP), tissue viability clinic (GP or self)		0/7
DN	Motability assessment (patient), rheumatology outpatients (GP)		0/2

Comment [V1]: 'm not sure this is lear

6.5.2 Hospital admissions

A comparison of the different rates of unplanned hospital admissions between the patients with different case manager types revealed that over the 9 months of the study, community matrons had the highest proportion of patients admitted (see table 50). This is despite their remit to reduce unplanned hospital admissions, but it is likely that it was a reflection of the complex patients that they were case managing compared with the other case managers and at what stage in their illness the patients had come on to the community matron's caseload. Six out of the 14 patients (30%) with CMs were admitted to hospital, on an average of two occasions, compared with 9% and 15% for nurse specialists and district nurses respectively. District nurse case managers had the highest proportion of patients visiting the Emergency Department and using general practice out of hours (OOH) services over the 9 months, 38% compared with 20% and 18% for community matrons and nurse specialists respectively.

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Table 50. Number of Hospitalisations, A&E/OOH use over 9 months

Patients received type of case managers (n=30)	Number of patients in hospital over 9 months	Mean number of admitted to hospital per patient	Number of patients visiting A&E and OOH	Mean Number of visits/use
CM (n=14)	6/14 (43%)	2	4/14 (29%)	2
CNS (n=9)	1/9 (11%)	1	2/9 (22%)	2
DN (n=7)	2/7 (29%)	2	5/7 (71%)	2
Totals	9/30 (30%)	2	11/30 (37%)	2

6.5.3 Refusal of services

It is known that patients with advance chronic disease frequently refuse treatment or services which are suggested or offered to them. (Rothman et al 2007) Thus the service use of the study patients cannot be seen in isolation from their decisions whether or not to accept the suggested contact or referral and, if they do decide to access a new service, their experiences of using it. Across the three sites, 16 out of the 51 patients (31%) refused one or more of the services that they were offered (see table 51). A range of services were refused by both patients and their carers for various reasons. The majority of service refusal was by community matron patients 11 out of 21 (52%). This may be explained partly by the fact that they were in receipt of the largest range of services out of all the nurse case managers. Home care workers were the service that was most frequently refused; nine out of 51 (18%) patients rejected this service usually on the grounds that they did not want to lose their independence. Such a means tested service would also have incurred charges for many.

Table 51. Number and type of service refusal across all sites

Patients received type of Case Manager	Number of patients refusing services	Types of service refused
CM (n=21)	11 (52%)	Home care workers, rehabilitation team, physiotherapist, respite care, social security benefit check and advice, secondary care
CNS (n=13)	2 (15%)	Home care worker
DN (n=11)	3 (27%)	Home care worker, secondary care
Total	16/51 (31%)	

Various reasons were given for refusal of other services. In some cases previous negative experiences made older people reluctant to apply for services which they may have been entitled to. Not meeting the criteria to apply for work acquired disease compensation meant that one older person subsequently refused any other services including home care workers and

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benefits. His carer also refused respite care on his behalf and attended to his hygiene needs if he was admitted to hospital. Other examples of service refusal related to the older person's perception that they possessed enough knowledge about their health already and felt they were being patronised by health care professionals:

"They (doctor) offered to send someone to show me how to use inhalers, but I refused because I already know. I also saw a dietician once for my brittle bone disease who wanted to show me how to walk which I thought was ridiculous." Community Matron Patient

6.6 Nurse case manager activities for patients

Each of the nurse case managers were asked at baseline and then subsequently each month how often they visited the patients and what care they had provided .

6.6.1 Comparison of contact and activities performed between types of nurse case manager

The level of contact between nurse case managers and their patients was quite variable across the sample. At baseline it ranged from between six monthly visits to two visits per week. Clinical nurse specialist's visits or clinic appointments had two patterns of contact, those who assessed their patients once and then referred them to other services for ongoing care and assessment (n=4), and those who saw them regularly (n=9). For those seen regularly, there was little difference in the mean monthly contact rate between the community matron and the nurse specialists who had regular contact with their patients, 3 and 2 visits per month respectively (see table 52).

The district nurse case managed patients had the lowest mean number of monthly visits at baseline: 1 per month. Although, as this quote shows, contact frequency could rapidly change with an alteration in the patient condition.

"*District nurse visits when asked – for periodic diabetic test and urine sample. Comes when my carer contacts them, which is about every three months. They come more often to do dressings when leg ulcers get bad – have been visiting 3 times a week for the last two-three weeks because of a weeping heel ulcer. My carer lets them know when this is needed and the nurse comes very quickly when she calls them*." District nurse patient.

The nurse practitioner and care home nurse patients also assessed their patients initially before referring them onto other services for ongoing care. Community matron patients and one of the clinical nurse specialist whose focus was on rehabilitation of people with COPD, visited more frequently, and it was unusual for them not to have weekly contact with the patient supplemented by phone calls.

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Table 52. Range of frequency of nurse case manager contact with patients at baseline

Type of nurse case manager	Range of home or clinic contact per month to individual patients	Mean number of home or clinic contacts per month to individual patients
CM (n=21)	1 to 8 contacts per month	3
CNS (n=13)	Range: 8 contacts per month to once every 6 months	2
DN team leader (n=11)	Range: 4 contacts per month to once every 6 months	1
Care home support team (n=3)	1 initial visit then referral on to other services	0
Nurse practitioner (n=3)	1 initial visit then referral on to other services	0

Over the nine months data collection, community matrons maintained contact with the patient but the frequency and intensity of involvement diminished and increasingly patients' needs were absorbed either by other nursing and social care services. In fact, community matron patients had more referrals and involvement of health and social care services. There were examples of these case managers initiating referrals to physiotherapists, ophthalmic services, and podiatry. Even with the monthly interviews and review of care received it was very difficult to establish to what extent increased contact was a reaction to a change in the patient's condition or the nurse being proactive recognising that the patient's health was changing and deteriorating.

6.7 GP contact with patient and nurses

As with the nurse case manager contact levels, GP contact with individual patients was also very variable. Eight patients had no contact with their GP over the 9 months that their care was tracked, three of whom were case managed by the practice nurse. A further four patients had telephone contact only with their GP over this time period. Analysis of the patient contact with their GPs per month demonstrated a range from zero to 4 times a month (see table 53). The mean number of monthly contacts was less than once a month for all the patients with one of the main three types of case manager. The CM patients had a mean of 0.8 contacts per month compared with 0.3 and 0.4 for CNS and DN patients respectively. Differences between the models were small, but the community matron patients had the highest mean number of monthly GP contact as well as the greatest range of monthly contact compared with the nurse specialist and district nurse case managed patients.

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Table 53. Range and mean of monthly patient GP contact for patients who completed 9 months

Type of nurse case manager	Range of GP contact per month (practice or at home)	Mean number of GP contacts per month
CM (n=14)	0 to 4	0.8
CNS (n=13)	0 to 2	0.4
DN team leader (n=11)	0 to 3	0.3

Out of the total of fifty one patients, fifteen (29%) patients, in all three sites, reported repeatedly that GPs were reluctant to do home visits. In site 1 half of the patients recruited reported this as a problem. It was a particular concern for these older people as they tended to be either unable to leave the house, or to have very poor mobility and lacked access to suitable transport. Coupled with an exacerbation of their condition this made consulting a GP extremely difficult and stressful for them. In addition, arranging convenient appointment times was also problematic. This was a context specific issue that directly shaped both how the nurses worked with the patients and the value that patients placed on the nurses' case management activities. This is discussed in more detail in chapter 9.

"If it wasn't for them (district nurses) I don't know where I'd be, the doctor doesn't even come round here." District nurse patient

If patient/GP relationships were irretrievable, nurse case managers would also help patients to register with another practice. In two different sites community matron and a district nurse were involved in helping the patient to do this. At the other extreme, one patient talked about their GP being overly concerned about them, and phoning them at least three times a week, which contributed to their anxiety even though it was well meant.

6.7.1 GPs and nurse case managers

One of the aims of nurse case management is that patient service provision is planned and coordinated by one individual. It is reasonable to assume that community matrons, because of their increased contact with the patient, range of care provided and involvement of other services were more likely to involve the GP in decision making about referrals and changes in treatment decisions.

There were several examples of duplication of the activities by nurse case manager and GPs, for example, in relation to medication management. This was particularly true for the patients of clinical nurse specialists whose approach to case management was closest to a medical model of care. Patients described scenarios where even though the nurse specialist had made changes to their medication following a blood test, they were requested to make an appointment to see their GP for the same issue. Thus patients were put in a dilemma as to whether or not they should consult the GP, causing them inconvenience and anxiety.

One patient was upset when he was given conflicting advice from the GP and the Nurse specialist over the correct dose of his medications following a blood test taken by the nurse specialist. He felt that the doctor and nurse should have come to an agreement over the dose rather than both giving him different advice. Another patient described some friction between the nurse specialist and her GP over prescribing the medication for her cardiac condition. In another case a Nurse Specialist prescribed treatment for a patient which a GP disagreed with and made alternative arrangements for, again causing concern to the patient who preferred the treatment being given by the nurse who he felt to be an expert in his condition.

6.8 Nurse case managers and other nurses

Another potential source of overlaps in care was where patients had more than one nurse involved in their care. At baseline 12 out of the 51 patients (24%) were seeing at least one nurse, 10 of whom were being case managed by a community matron (see table 54). Thus half of the community matron caseload was receiving care from at least two nurses at the start of patient tracking, the second one being a district nurse in all cases. Once the Community Matron relationship had been established with the patients there was usually no duplication of care between District Nurses and CMs, although two patients did report having the same blood test take twice, by different nurses. Four patients reported having lung function tests carried out by both District Nurses and Community Matrons, although the Community Matron included this as part of a wider assessment and conducted a more detailed test. In three cases patients were confused about the difference between the nurses who saw them, and why they needed more than one nurse.

No District Nurse or Nurse Practitioner case managed patients were receiving care from two or more nurses from the point at which their care was tracked for the study.

By the end of the 9 month tracking period, an even higher proportion of community matron patients were receiving care from two nurses, 24% compared with 71% respectively (see table 55). There was only one other referral to another nurse over the nine month patient tracking, which was made by the nurse practitioner. As already mentioned, in all cases at baseline the second nurse was a district nurse, at nine months seven of the community matron patients were also under the care of a district nurse, two a cardiac nurse specialist and one a palliative care nurse. All referrals at both time points were made by the relevant nurse case manager.

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Table 54. Patients receiving care from 2 or more nurses

Type of nurse case manager	Patients with 2 or more types of nurses at baseline	Patients completing 9 months (n=32)	Patients with 2 or more types of nurses over 9 months
CM	10/21 (24%)	14	10/14 (71%)
CNS	1/13 (8%)	9	1/9 (11%)
DN	0/11	7	0/7
NP	0/3	3	1/3 (33%)
CHST	1/3 (33%)	0	None completed
Totals	12/51 (24%)	32	12/33 (36%)

6.9 Patient's health experience over nine months

As already discussed, the patient service use and health experiences were established through monthly patient and nurse case manager telephone interviews or visits over nine months. This information was put into a timeline for each individual patient. Each timeline reports the pattern of ill health and key events which individual patients experienced and the frequency of contact they had with the nurses and other services. Appendix 6 provides examples. This section provides a commentary on these timelines and draws on the patient interviews to illuminate how they represented their health and experiences over the nine months of data collection.

6.9.1 Exacerbations and patient deaths over nine months

The mapping of the patients over the nine months made explicit the fluctuating nature of their experience of health for the majority of the case managers' patients. Table 55 demonstrates how almost all the patients experienced exacerbations where their health worsened sufficiently that it required extra nurse case management input and treatment and or referral to GP or secondary services. The kind of exacerbations experienced were infections (e.g. respiratory, UTI and wound infections), hypoglycaemia, intransigent pain, transient ischaemic attacks, angina and respiratory difficulties, sudden deterioration in health or mental state. Also during this time seven patients had falls which affected their mobility and function. Of the eleven that died three had had falls prior to their death. Only six of the patents had no complications or exacerbations in their condition over the time of data collection (see examples of timelines 10, 24, in appendix 6), two clinical nurse specialists' patients, one community matron patient, two district nurse patients, and one nurse practitioner patient.

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Table 55. Number of exacerbations and falls over nine months for patients that completed the nine months data collection

	Patients' type of nurse case manager				
Exacerbation of condition or fall (number)	Community matron	Clinical nurse specialist	District nurse	Care home case manager and Nurse practitioner	Total
0	1 (1)	2 (2)	2	1 (2)	6(5)
1-4	3	4(1)	3	(1)	10 (2)
5-9	8	2	2	(1)	12(1)
10 or more	2	2	0	0	4
Patients who died	6	0	4	1	11
Total numbers	20(1)	10(3)	11	2 (4)	51

NB the numbers in brackets patients who agreed to notes only reviews at the beginning and end of the study, hence no timelines were available for them.

It might have been anticipated that the number of exacerbations and falls experienced by patients would be clustered in the first three to four months and diminished over time. However, this was not evident in the patient trajectories shown in the timelines. The majority of patients they experienced a significant episode of further ill health during the data collection period and for 18 patients this occurred every one to two months. Rather than reducing the number of exacerbations it appeared more likely that having a nurse case manager involvement and related services meant that episodes of ill health were responded to quickly, were less severe, or were perceived by the patient to be better managed and less anxiety provoking. For example, a patient with COPD and CHD who lived alone had been three months on the clinical nurse specialist's case load prior to joining the study. In the first three months of data collection there were seven exacerbations of her COPD that required intensive pulmonary rehabilitation, the involvement of the rapid response team, out of hours GP support as well as almost daily visits from the case manager. By the end of the study the patient was being supported by weekly case manager visits because she felt more confident in managing her symptoms. Nevertheless, every month in the last three months of data collection the patient had out of hours input for COPD related symptoms.

A few patients did experience a noticeable improvement in their health as a result of intensive case/disease management by community matrons and clinical nurse specialists and the involvement of other services. For example one patient was initially case managed by the community matron for weight loss and pain control but then deteriorated as a result of heart failure and anaemia and was subsequently referred to the nurse specialist for further support (See appendix 6, patient 6)). By the end of nine months her heart failure had stabilised, she was less anaemic and she had put on weight:

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"I'm better definitely. I was frightened of doing too much and making my heart worse, but now I do a lot more around the house and go to the shops." Community matron patient

6.9.2 Quality of Life

The Euroquol thermometer (given in appendix 4) scores were a subjective measure of participants' quality of life that acted as a snapshot of how the older person was feeling over the nine months of data collection. Table 56 shows those participants who perceived that their situation was improving or deteriorating and reflects in part the fluctuating experience of health related events described above The Stanford measure of self efficacy similarly, did help to identify those patients who perceived themselves to be improving in their ability to manage and live with the symptoms of their illness.

Table 56. Perceived improvement in quality of life

Trajectory of quality of life scores over 9 months (EUROQUOL scores)	Patients' nurse case manager model			
	CMs	CNS	DN	NP and CHST
Incremental Improvement in Euroquol scores	3	2	1	
Euroquol scores improved	1	4	3	2
Deterioration in Euroquol score	4	1	1	
Fluctuating score from month to month	9	6	2	1
Total	17	13	7	3

Sixteen out of twenty one patients (76%) who answered the self-efficacy questions in months 1 and 9 reported an improvement in their self efficacy, two reported little or no change and three reported deterioration (table 57). This would seem to indicate that case managing nurses have a positive effect on self efficacy, However, not all patients were able to answer the self efficacy questions in each interview, particularly those who became more ill or who had cognitive or other impairments that deteriorated during the study, so this data may be somewhat skewed towards patients who improved in their self efficacy whilst not fully describing the situation for those that deteriorated.

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Table 57. Changes in patient perceived self efficacy over nine months

Trajectory of Stanford Self – efficacy scores over 9 months	Patients' nurse case manager model		
	CMs	CNS	DN
Overall improvement in self efficacy scores	7	4	5
Minimal change in self efficacy scores	1	1	0
Deterioration in Self efficacy scores	2	1	0
Total (n=21 over 9 months)	10	6	5

NB Comparison of 21 patients responding in months 1 and 9. Insufficient data for nurse practitioner and care home case manager

6.9.3 Accumulation of problems and challenges to health

The preceding sections have summarised service use, key events, and measures of well being. The patient interviews enabled us to understand how the older people themselves represented their day to day experience of living with a long-term condition.

The principal underlying causes of chronic disease were often not considered by patients to be their main condition. On a day to day basis it was the problems of pain and discomfort, lack of mobility and personal distress or worry about developing dementia that affected their quality of life and understanding of their health needs.

Participants often talked about how tired they felt, which could affect their ability to complete the interviews and were often a marker of a gradual deterioration. Some participants had no difficulty taking part in an interview at the beginning, but found it a tiring experience by the end. This was most evident for the patients of the community matrons, the care home case manager, and the clinical nurse specialists that had a specialist remit for people with COPD and CHD. Twenty eight of 51 patients identified persistent tiredness as having a direct impact on their ability to perform everyday tasks, their health, and sense of wellbeing.

Tiredness and feeling depressed were inextricably linked .For some patients, having more energy and feeling "less down" were the examples given of how their quality of life had improved since joining the study. These participants also demonstrated improvements in their overall confidence and well being. As can be seen from the quotes below, being less tired and able to do more increased confidence

"*Better than ever... I haven't felt this good for years. I can get out and about a bit more now, like I can walk down the road to the little shop there. It's not much, I know, but a year ago I couldn't have done it. I was too ill, and always so scared of getting part way there and getting stuck*." Community matron patient (Euroquol scores 45/100 at baseline end of data collection was 80/100).

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For some of these participants (but not all) symptom management through medication changes or strategies to control breathlessness by their clinical nurse specialist meant they experienced less fatigue. As one participant put it, following a day out, they were now tired "*for a good reason*".

A recurring issue of concern raised by patients and carers was sight loss and the impact that this had on their ability to maintain independence. This was referred to as a reason for lost confidence, depression, and pessimism about the future. There were also examples of how this had contributed to falls and increasing feelings of isolation. One patient suffered from severe COPD but following pulmonary rehabilitation had been able how to deal with this. This patient felt that her main problem was how to cope with her increasing sight loss and the problems she had with this and her fear of becoming blind:

"*My breathing, well, it's bad as you know, my lungs have had it but at least they showed me what to do about it. The main thing now for me is this macular degeneration. One day I could see fine, the next day I woke up and one I had gone almost completely. It was terrifying, and they say the other one will probably go soon. That's far more worrying than my lungs – how will I cope if I can't see*?" Community matron patient

There were three examples in two of the sites of community matrons helping a participant to obtain a referral for cataract surgery with very positive outcomes and reported quality of life for the individuals concerned.

Bereavement

Almost a quarter of patients had experienced a bereavement of spouse or close friend or relative which affected their emotional health. The death of a wife or husband may have happened several years ago; however it was a loss that was referred to in interviews as directly influencing their health and general ability to cope. During the data collection there were two examples of partners dying. The older people were aware of how the death of neighbours and friends reduced their network of support and increased their sense of isolation. The regular contact and nursing input from the community matrons and one of the clinical nurse specialists was consistently acknowledged as an important source of support. Apart from regular contact and providing a "listening ear" there was little reported evidence of what the nurse case managers did in these situations. There were two examples of different community matrons working to provide care alternatives for the recently bereaved. One woman after the unexpected death of her husband, attributed her being willing to carry on living, as due to the extra service support the community matron had arranged for her. The community matron liaised with the daughter of a recently widowed man who was becoming increasingly confused, to discuss and arrange alternatives to him staying at home alone.

Approaching the end of life

Nurses had been asked to introduce patients to the study who they anticipated would live for a year. Nevertheless there were 11 deaths and

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many of the patients on the case managers' caseloads were approaching the end of their life with two patients receiving a diagnosis of terminal cancer following several months of symptoms of increasing pain and referrals to different services for investigations. Clinical nurse specialists talked of patients following a "typical trajectory for heart and lung failure". For only one case manager with a specialist interest in COPD was a patient's failure to respond to treatment a reason for not keeping them on the caseload.

During the interviews older people talked about their awareness that they were in the last months and years of their life, this was particularly true for patients that were receiving care from community matron and the clinical nurse specialist patients that had heart failure. For these patients being able to plan their care and have realistic conversations with their case manager was helpful. Nurses talked of planning support for their patients and liaising with palliative care services, discussing medication regimes and ensuring advance care plans were in place. Appendix 6 illustrates how one older patient's difficulty with breathing became progressively worse and how the community matron anticipated her future care needs and progressively built up the level of support she received to include respite, social care and palliative care services. The community matron provided chest physiotherapy to relieve symptoms alongside the other regular monitoring activities she had always fulfilled for the patient. For this community matron the dilemma was that handing the patient over to other services for end of life care represented a significant break in the continuity of services.

There were older people who knew that they were approaching the end of life but who either had not had the opportunity to discuss this with their case manager or had not thought it appropriate. On two occasions the researcher was the first person who the older people confided in about how they did not want any further treatments or interventions, once for the patient of a district nurse and once a patient of a care home case manager. A possible unintended consequence of the patient having regularly talked in detail about their health with the researcher over a nine month period:

"*I am getting ill inside, I can feel it but I don't want them to operate again because I don't think I would survive it anyway. I am more at ease with it all than I was and feel that if I am going to go I should do it as comfortably as I can and that I don't want anyone to stop it happening. I feel, kind of resigned to it all I suppose you could say*".

"*I think I was scared about it for a long time but it feels like someone turned a light on inside and it is ok now. I wanted to let you know what I want to happen when the time comes because I don't want them forcing things on me that I don't want and I definitely don't want to go under the knife again*."*. Care home case manager patient

* The researcher asked for (and was given) the older person's permission to let the care home manager know their wishes and to have the opportunity to talk further about their wishes for end of life.

Although this patient had not discussed their views about approaching the end of life, the nurse case manager had described how her involvement and role as case manager was often to help care home staff begin to recognise when someone was dying and help them ensure they understood the older person's wishes and involve palliative care services. The care home case manager described her role in this situation as one of watchful waiting.

6.10 Comparison of GP records and patient and nurse reports

As a reliability check on the information received from the nurses and patients on services used we asked the patients' GPs if we could review their notes. Only a small number of GPs agreed to provide a patient notes review for the year prior to their patient's participation in the study as well as the nine months of their participation, despite signed patient consent and the offer of financial reimbursement of practice staff time (n=7 in site one n=5 in site two n=5 in site three). The GP notes reviews were used to plot service use, treatments, and investigations as recorded in GP notes over the nine months (known as the GP timelines). This was used as a validity check for the patient reported events over the nine months (the patient timelines).

When compared with the patient timelines all (15) but two of the GP timelines showed omissions The most common missing data was on community matron and nurse specialist contacts, for example on one patient timeline the community matron had made 27 visits to the patient compared with three recorded on the GP timeline. Other services which were absent from the GP timelines included counselling and physiotherapy, in each instance the patient had reported that the GP referred them to that service, and patients also reported some hospital admissions which were not recorded on the GP records. Conversely some GP consultations were absent from patient timelines but no other services reported by the GP were absent. Given the small number of GP notes which were reviewed it is not possible to draw firm conclusions. In most parts of the country community nurses are required to record their activities on patient record systems that are either paper based or, if electronic, do not interface with general practice records (Audit Commission 1999). Some GP attached community nurses in the study has shared records with the GP so they were inputting data onto the same systems. GP perceptions from the stakeholder analysis in all sites reported that communication between community nursing services and general practice was a problem (chapter 11). One GP reported that the recent local change for district nurses to add to the general practice notes was an asset in understanding nursing contact with patients.

6.11 Discussion

In summary, at baseline, patients were similar in the range of age, household circumstances, and types of housing across the types of nurse case managers. The community matrons' patients were more likely than patients of other nurse case managers to be socially isolated and their social

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isolation was an explicit contributory factor in their admission to case management. Most of the patients of the community matrons and district nurse case managers were in receipt of state benefits (other than state pension), while a smaller proportion of patients of the clinical nurse specialists was in receipt of similar benefits.

The common conditions amongst patients of all types of nurse case manager were COPD, CHD, diabetes, and strokes. All had more than one condition with the clinical nurse specialist patients likely to have the least number of co-morbidities and the community matron patients most likely to have over three conditions and be on the most medications. The clinical nurse specialist patients were the least dependent of the patient groups and they were not reliant on others for activities of daily living and none had cognitive impairment.

The majority of patients had multiple health and social care needs. The patients of community matrons were referred to more services than the models of care and had more complex needs and episodes of ill health.

The tracking of the patients' experience over nine months highlighted the very different patterns of nurse case manager contact and range of activities (see also chapter 8).

This chapter has shown that whilst nurse interventions were appreciated, and most services (but not all), for many, fluctuating health and quality of life unexpected episodes of acute illness and deterioration were common experiences. Many of the patients were experiencing multiple losses and in the last few years of life. The involvement of the nurse case manager, most notably the community matron had the potential to increase the services' responsiveness and in some situations compensated for inadequate provision in other parts of the organisation. Nevertheless, the nine months data collection highlighted that case manager involvement for patients with multiple needs could not of itself prevent unplanned hospital admissions and out of hours care. Chapter 8 picks up these issues and discusses in more detail how the process and impact of case management was understood by the patients of the different models.

The next chapter addresses the questions of costs related to the different case manager models

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7 Economic analysis

7.1 Introduction

This chapter addresses questions of the economic analysis in the case studies. It aims:

- To investigate the caseloads and activities undertaken by nurse case managers recruited to the study, and to estimate cost per case-managed patient.
- To analyse the use of health and social services of patients recruited to the study by the nurse case managers, and to estimate total cost of service provision at patient level.
- To explore the patient demographic and health factors associated with resource use and costs, and in particular the:

a) Differences between the characteristics of patients recruited to the study by community matrons and those of patients recruited by other types of nurse case managers;

b) Differences between the characteristics of patients recruited to the study from the three different sites;

c) Association between patient characteristics and total cost per patient per month;

d) Association between patient characteristics and mean nurse case manager time per patient per month;

e) Association between nurse case manager time per patient per month and patient utilisation of other services (other nurses, GP, other health professionals, A& E, outpatient) to determine whether nurse case managers are substitutes (reduce need) for other services, or whether they marshal extra services for clients;

f) Patient and service delivery factors that might predict hospitalisations. To investigate the caseloads and activities undertaken by nurse case managers recruited to the study, and to estimate cost per case-managed patient.

7.2 Nurse case manager caseloads and activities

The typical working weeks of the twelve nurse case managers recruited from the three study sites (city, coast and shire, n=4 per site) were investigated using specially designed weekly diaries. Nurse case managers were asked to record the type of activities (in particular, case management vs non-case management) and tasks engaged in and, for each activity/task,

the duration in minutes and setting (e.g. patients' homes, clinics, hospitals). Each working day was divided into two sessions – morning and afternoon. The diaries were available in two formats, electronic and paper. Initially, it was intended that the weekly diaries were to be completed once every month for the full duration of the study (9 months). However, several nurse case managers reported that completing the diaries was too onerous and time consuming. Pragmatically, in order to minimise attrition, nurse case managers were asked to complete the weekly diaries at two time-points, at the start and at the end of the study.

The data in the diaries were collated and analysed under key headings to describe eight groups of activities/tasks: time with case managed patients; time with non-case managed patients; administration (including all record keeping); travel; liaison with other professionals (e.g. GPs, allied health professionals, social work staff); management activity (e.g. team and staff management); Trust-related activity (e.g. attendance at and representation on Trust meetings or events); any continuing professional development (CPD) activities. Once the data for each nurse case manager's diary had been analysed under these eight broad categories, a mean value for the time spent on each activity group over the reported weeks, pro rata to their contracted hours, was calculated to represent the time spent on that activity group for a typical working week. The total caseloads of each participating nurse case manager and the proportion of their caseload that was case managed were obtained from the interview data. The cost per case managed patient was calculated for each nurse case manager by applying the proportion of each nurse case manager's caseload that was case managed to the annual cost of the nurse speciality. Costs were obtained from validated national sources (Curtis 2008) and were inclusive of all overheads and qualifications.

7.2.1 Findings

The sample of twelve nurse case managers included four community matrons, one nurse practitioner, three community nurse specialists (cardiac, COPD, tissue viability), three district nurses and one care home specialist team manager. All but three nurse case managers completed full weekly diaries for both time-points.

The results of the analysis of the nurse case manager activity diaries are shown in Table 58. Community matrons and the cardiac nurse specialist reported exclusive case management roles. For all other nurse case managers, case management was a relatively small part of their total caseload. The mean annual cost per case managed patient varied with nurse speciality and caseloads, ranging from £169 to over £3000. It was highest for the community matrons who were engaged exclusively in case management but had relatively small caseloads (Table 59).

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Table 58. Nurse case managers' caseloads and time allocations for various activities

Site	Nurse case man-ager model	Based on interview data:			Based on nurse case managers' diaries:								Total time
		No. on case-load	Case managed caseload		Mean time in hours per week (proportion of total time, %) spent with/on:								
			No.	Pro-portion (%)	Case managed patients	Non-case managed patients	Admin	Travel	Liaison with other professionals	Manage-ment activity	Trust activity	CPD	
1	CM	20	20	100	16.1 (44.2)	0	8.5 (23.4)	3 (8.2)	7.6 (20.9)	0	0	1.2 (3.3)	36.4
2	CM	30	30	100	11.1 (30.0)	0	6.3 (17.0)	4.4 (11.9)	6.7 (18.1)	3.7 (10)	3 (8.1)	1.8 (4.9)	37
2	CM	32	32	100	14.9 (40.0)	0	5.6 (15.1)	4.1 (11.0)	7.4 (19.9)	1.5 (4.0)	0.7 (1.9)	3 (8.1)	37.2
3	CM	42	42	100	10.8 (29.2)	0	7.8 (21.1)	2.2 (5.9)	7 (18.9)	1.8 (4.9)	1.5 (4.1)	5.9 (15.9)	37
1	DN	300	15	5	3.2 (8.6)	16.3 (44.1)	4.1 (11.1)	6.4 (17.3)	3 (8.1)	4 (10.8)	0	0	37
2	DN*	110	15	13.6	3.1 (8.4)	14.8 (39.9)	1.5 (4.0)	2.3 (6.2)	1.1 (3.0)	12.1 (32.6)	1.7 (4.6)	0.5 (1.3)	37.1
3	DN	481	22	4.6	2.1 (5.7)	13.3 (35.9)	1.5 (4.1)	3.6 (9.7)	2.8 (7.6)	9.7 (26.2)	1.8 (4.9)	2.2 (5.9)	37
1	CNS	75	75	100	22.4 (60.5)	0	8.9 (24.1)	3.4 (9.2)	2.3 (6.2)	0	0	0	37
2	TNS	490	26	5.3	2.5 (6.8)	4.8 (12.9)	4.2 (11.4)	4.5 (12.2)	3.4 (9.2)	10.1 (27.3)	4.3 (11.6)	3.2 (8.6)	37
3	RNS*	610	60	9.8	5.3 (14.4)	10.8 (29.2)	2.9 (7.8)	3.3 (8.9)	2.3 (6.2)	8.7 (23.5)	3 (8.1)	0.7 (1.9)	37
1	NP*	n/a	43	n/a	19.9 (53.8)	0	7 (18.9)	6.7 (18.1)	3.4 (9.2)	0	0	0	37
3	CHST	621	25	4.0	3.3 (11.0)	0	3.6 (12.0)	3 (10.0)	3.6 (12.0)	11.4 (38.0)	3.6 (12.0)	1.5 (5.0)	30
Mean		255.5	33.8	49.3	9.6 (26.1)	5 (13.5)	5.2 (14.2)	3.9 (10.7)	4.2 (11.6)	5.3 (14.8)	1.6 (4.6)	1.7 (4.6)	36.4
SD		249.53	18.41	48.62	7.34 (19.70)	6.75 (18.24)	2.66 (6.94)	1.43 (3.80)	2.29 (6.2)	4.79 (13.91)	1.55 (4.48)	1.74 (4.68)	2.01
Min		20	15	4	2.1 (5.7)	0	1.5 (4)	2.2 (5.9)	1.1 (3)	0	0	0	30
Max		621	75	100	22.4 (60.5)	16.3 (44.1)	8.9 (24.1)	6.7 (18.1)	7.6 (20.9)	12.1 (38)	4.3 (12)	5.9 (15.9)	37.2

*based on data from 1 diary week, No.Number, CMCommunity Matron, DNDistrict Nurse, CNSCardiac Nurse Specialist, TNSTissue Nurse Specialist, RNSCOPD Nurse Specialist, NPNurse Practitioner, CHSTCare Home Specialist Team Manager, n/anot available, SDStandard Deviation, MinMinimum value, MaxMaximum value

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Table 59. Nurse case management: cost per patient

Site	Model/ working arrangements	*Salary base cost (£)	Based on interview data:		Case managed salary cost (£)	Cost per case managed patient (£)
			Proportion (%) of total caseload of case managed patients	No. of case managed patients (based on interview data)		
1	CM 1.0 FTE	61,880	100	20	61,880	3,094
2	CM 1.0 FTE	61,880	100	30	61,880	2,062.67
2	CM 1.0 FTE	61,880	100	32	61,880	1,933.75
3	CM 1.0 FTE	61,880	100	42	61,880	1,473.33
1	DN 1.0 FTE	50,790	5	15	2,539.50	169.30
2	DN 1.0 FTE	50,790	13.6	15	6,907.44	460.50
3	DN 1.0 FTE	50,790	4.6	22	2,336.34	106.20
1	CNS 1.0 FTE	50,785	100	75	50,785	677.13
2	TNS 1.0 FTE	50,785	5.3	26	2,691.61	103.52
3	RNS 1.0 FTE	50,785	9.8	60	4,976.93	82.95
1	NP 1.0 FTE	61,880	^100	43	61,880	1,439.07
3	CHST 0.8 FTE	50,790	4	25	1,625.28	65.01
Mean		55,409.58	53.5	33.8	31,771.84	972.29
SD		5,711.662	48.61	18.41	29,704.09	1,008.90
Min		50,785	4	15	1,625.28	65.01
Max		61,880	100	75	61,880	3094

*based on data in Curtis, 2008, including overheads and qualifications, ^assumed 100% as case managed proportion could not be ascertained, CMCommunity Matron, DNDistrict Nurse, CNSCardiac Nurse Specialist, TNSTissue Nurse Specialist, RNSCOPD Nurse Specialist, NPNurse Practitioner, CHSTCare Home Specialist Team Manager, FTEFull Time Equivalent, SDStandard Deviation, MinMinimum value, MaxMaximum value

7.3 Patient level analysis of nurse case manager input, other service use and costs

The twelve nurse case managers representing four different models (community matrons, nurse practitioners, nurse specialists, district nurses)

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across the three sites recruited a total of 51 patients to the study. Patients, and carers where applicable, and if consented to participate, were assessed by the study researchers once every month over the nine month period, either through face to face interviews (at baseline (month 1), middle (month 5) and end (month 9)) or by telephone (months 2, 3, 4, 6, 7, 8). The interviews were semi-structured and data for the economic evaluation were extracted from responses and entered into a purpose-designed SPSS database. The database consisted of eighty variables covering:

- Patient background information and clinical factors: age, gender, ethnicity, main language and education level, living and carer situation, main condition, number of co-morbidities and medications, aids, Barthel (dependency) Index, EQ5D (health related quality of life – thermometer (0 worst imaginable – 100 best imaginable), and utility score (-.59 – 1.0), Kingshill Cognitive Test (CIT), Geriatric Depression Scale (GDS), Self Efficacy Scale
- Patient use of services/practitioner contacts: nurse case manager; other health care professionals including nurse specialists, district nurses, practice nurses, GPs, allied health professionals; hospital based services including outpatient clinics, A&E, day and inpatient admissions; other, including hospice stays; transport; social care including Careline, meals on wheels, care assistance; voluntary services; privately purchased help, including home help, professional consultations; unpaid informal care from family and friends
- Carer background information: age, gender, relationship, living arrangements, health status, hours spent caring, Carer Strain Index

Measures were entered at baseline, and changes were recorded on a month by month basis, as necessary. Data reported by patients/carers were checked through nurse case manager interviews at the start and end of the observation period. Information on tests conducted by nurse case managers was also obtained by this method and entered into the database to further inform the type of services delivered to patients. Plans for nurse case managers to keep records of their activity with each patient they recruited (i.e. visits, telephone calls, meetings, correspondence etc) were dropped because piloting showed the task to be too time consuming and onerous.

NHS and social care costs per month were calculated from available data on resource use. The mean monthly utilisation of each item of service use was calculated for each patient in the analysis. Unit costs were obtained from validated national sources (Curtis 2008, DH 2008) and applied to each category. In hospital costs were estimated according to the reason for admission. Full details of the computational methods are given in Appendix 7. The total monthly cost per patient was obtained by summing the cost of each individual service use item. Use of voluntary services and informal caring were not included in the costing exercise. Similarly, private (patient) expenditures on aids, home help, travel etc were not estimated.

7.3.1 Findings

Eighteen of the 51 patients recruited to the main study were not included in the economic analysis because less than three months of service use data were available: six died within 3 months of entering the study and the

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remaining twelve withdrew from the study (one due to the death of the partner, and the others for unknown reasons). Hence, the economic analysis was undertaken on 33 patients, all of whom had supplied data for more than three months (Site 1 n=12 [community matron 5, NS 5, nurse practitioner 1, DN 1]; Site 2 n=15 [community matron 9, NS 4, DN 2]; Site 3 n=6 [community matron 2, DN 4]). Of the remaining 33 patients, 27 completed the full nine month observation period, while eight months of data were available for a further two participants.

Background social and demographic information about patients included in the economic analysis, organised by site and nurse type, is shown in Table 60. Data showing health status variables are shown in Table 61. Although measures of Barthel (dependency), CIT (cognition), GDS (depression), and Self Efficacy were collected at each of the three face to face interviews (start, middle, end), there were many missing observations and only baseline data (or the nearest available observation) are shown. EQ5D (health-related quality of life) scores were collected monthly (by phone and face to face interview), and values from the earliest, middle and latest available observations are shown. A comparison of characteristics of the 33 patients included in the economic analysis with those of the main sample of 51 patients at baseline is shown in Table 62. The sample in the economic analysis contained a larger proportion of men. On average they reported less co-morbidity and fewer prescribed medications than the total sample. However, statistical tests of difference between the groups were non-significant for all variables.

Use of health and social care, nurse case managers, tests, other healthcare professionals, hospital care, social services, care assistants, voluntary services, privately purchased services and informal (unpaid) care are shown in Tables 63, 64 and 65. Consistent with smaller caseloads and exclusive focus on case management, community matrons provided greater input to their patients than did the other nurse case manager models. The highest contact time recorded per month was by the community matrons in Site 2 (coast), who spent approximately 800 minutes/month with some individual clients. The lowest contact time recorded per month was by patients who were case managed by specialist or district nurses (less than 20 minutes per month).

Variability between sites in use of other healthcare resources is observed. District nurses were used by more patients in Sites 2 and 3, and patients reported more use of GPs in Site 1. Generally, patients in Sites 2 and 3 were more likely to see healthcare professionals in their own homes. There were no planned hospitalisations in Site 1. Some patients in each site were admitted for unplanned hospital care during the course of the study. There were scattered missing service use data amongst the sample, particularly in the areas of social care and the voluntary sector. The live-in partners of six patients did not take part in the study so the details of the informal care that they provided were not available.

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The total monthly costs per case managed patient over the study period, and the cost components, are shown in Table 66. Total costs ranged from £4315 (Site 1, Nurse 1, Patient 6: a 79 year old male, main diagnosis heart failure, managed by a cardiac nurse specialist, with 40 unplanned hospital days) to £65 (Site 1, Nurse 1, Patient 3: a 73 year old woman, main diagnosis heart failure, managed by the same nurse specialist), with no unplanned hospital days. The mean monthly cost of the 33 patients in the study was £854 (SD 995).

Two main factors account for high patient costs over the study period: hospitalisations and intensive case management. The mean monthly cost of nurse case managers in this study is £302, but considerable variability was observed (SD 358; Range £8 – £1190). The community matrons in site 2 (coast) spent time valued at over £1000 per month on each of four of their patients, and the costs of a further two patients were over £700 each per month. Some, but not all of the patients receiving intensive nurse case management input reported lower use of other services. The association between patient demographic and health factors and service use and costs is explored in more detail in the next section.

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Table 60. Background information on the 33 patients included in the economic analysis

Patient ID	Nurse Case Man-ager type	Months on caseload before study	Months of available data	HEALTH						DEMOGRAPHICS					SOCIAL			
				Primary condition	No. of comorb	No. of meds	Anti-deps	Aids varied	Aids Payer	Age	Sex	Ethn	Eng 1st lang	Educ level	Live alone	Accommodation Type	Accommodation Own/ rented	Bene -fits
Site1N2P1	CM	5	9	COPD	3	13	No	Yes	SS some/all	74	M	W	No	≤16	No	Ind	Rent	No
Site1N2P2	CM	2	9	COPD	2	10	No	Yes	SS all	80	F	W	Yes	≤16	Yes	Sup	Rent	Yes
Site1N2P3	CM	15	9	COPD	4	10	No	No	-	91	M	W	Yes	≤16	Yes	Ind	Rent	Yes
Site1N2P4	CM	22	9	COPD	4	8	No	No	-	86	F	W	Yes	≤16	Yes	Ind	Own	Yes
Site1N2P7	CM	1	9	HF	5	9	No	Yes	SS some	80	F	W	Yes	≤18	Yes	Ind	Rent	Yes
Site1N1P2	CNS	4	9	HF	2	4	No	No	-	75	F	W	Yes	≤16	Yes	Ind	Rent	No
Site1N1P3	CNS	0.75	9	HF	3	8	Yes	No	-	73	F	W	Yes	FE	Yes	Ind	Own	No
Site1N1P4	CNS	3	9	HF	2	3	No	No	-	67	M	W	Yes	≤16	No	Ind	Rent	No
Site1N1P5	CNS	3	8	HF	4	11	No	Yes	SS all	75	F	B	Yes	-	No	Ind	Own	Yes
Site1N1P6	CNS	6	9	HF	4	10	No	No	SS some	79	M	W	Yes	≤16	Yes	Ind	Own	Yes
Site1N3P1	DN	2	9	Leg ulcers	3	1	No	Yes	SS all	65	F	W	Yes	≤16	Yes	Sup	Rent	Yes
Site1N4P3	NP	2	9	MD	4	5	Yes	Yes	Pt all/SS all	77	F	W	Yes	≤16	No	Ind	Own	No
Site2N5P1	CM	4	9	COPD	1	8	No	Yes	SS all	72	M	W	Yes	≤16	No	Ind	Own	Yes
Site2N5P3	CM	4	9	HF	3	4	Yes	Yes	Pt all	81	M	W	Yes	≤16	No	Ind	Own	Yes
Site2N5P4	CM	2	9	COPD	4	16	No	Yes	SS some	91	M	W	Yes	≤12	Yes	Ind	Own	Yes
Site2N5P5	CM	2	5 (RIP)	HF	1	16	No	Yes	Pt all	91	M	W	Yes	≤16	Yes	Ind	Own	Yes
Site2N6P1	CM	4	8	Leg ulcers	4	9	Yes	Yes	SS all	72	F	W	Yes	FE	Yes	Ind	Own	Yes
Site2N6P2	CM	2	9	HF	3	5	No	No	-	79	M	W	Yes	≤16	No	Ind	Rent	Yes
Site2N6P3	CM	1	9	COPD	2	4	No	Yes	SS some	65	F	W	Yes	≤16	Yes	Ind	Own	Yes
Site2N6P4	CM	5	9	DM	5	12	No	Yes	SS some	91	F	W	Yes	≤18	Yes	Ind	Rent	Yes
Site2N6P5	CM	3	9	COPD	4	8	No	Yes	SS all	70	M	W	Yes	≤16	No	Ind	Own	Yes
Site2N7P1	TNS	6	9	Leg ulcers	3	8	Yes	No	-	64	M	W	Yes	≤16	Yes	Ind	Own	No
Site2N7P2	TNS	2	5	Leg ulcers	2	2	No	No	-	78	F	W	Yes	≤12	No	Ind	Own	Yes
Site2N7P4	TNS	1	9	HF	2	8	No	No	-	72	M	W	Yes	≤12	Yes	Ind	Own	Yes
Site2N7P5	TNS	5	9	Leg ulcers	2	2	No	No	-	69	F	W	Yes	≤18	No	Ind	Own	Yes
Site2N8P1	DN	2	9	HF	3	9	No	Yes	Pt all	80	M	W	Yes	≤16	No	Ind	Own	Yes
Site2N8P5	DN	1	4 (RIP)	Dementia	4	5	No	No	-	94	F	W	Yes	≤12	Yes	Sup	Rent	Yes
Site3N9P3	CM	1	4 (RIP)	CVA	3	7	No	No	-	79	M	W	Yes	≤16	Yes	Ind	Own	Yes
Site3N9P5	CM	7	9	COPD	3	3	No	Yes	SS some	96	F	W	Yes	FE	Yes	Ind	Own	Yes
Site3N10P1	DN	1	9	CVA	1	3	No	Yes	SS all	78	M	W	Yes	≤16	No	Ind	Own	Yes
Site3N10P2	DN	2	9	MD	2	5	No	Yes	SS some	71	F	W	Yes	≤16	Yes	Ind	Rent	Yes
Site3N10P3	DN	3	9	MD	2	9	Yes	Yes	SS all	68	M	W	Yes	≤16	Yes	Ind	Own	Yes
Site3N10P4	DN	-	9	MD	-	3	No	Yes	SS some	88	F	W	Yes	≤16	No	Ind	-	Yes
Mean		3.9	8.4		2.9	7.2				77.9								
SD		4.28	1.50		1.11	3.87				8.95								
Min		.75	4		1	1				64								
Max		22	9		5	16				96								

[CM]Community matron, [CNS]Cardiac Nurse Specialist, [DN]District Nurse, [NP]Nurse Practitioner, [TNS]Tissue Nurse Specialist, [RIP]Deceased, [COPD]Chronic obstructive pulmonary disease, [HF]Heart Failure, [MD]Macular Degeneration, [DM]Diabetes Mellitus, [CVA]Cardiovascular accident/stroke, [No.]Number,

[comorb]comorbidities, [meds]medications, [Anti-deps]Antidepressants, [SS]Social Services, [Pt]Patient, [M]Male, [F]Female, [Ethn]Ethnicity, [W]White, [B]Black British, [Eng 1st lang]English 1st language, [Educ level]Education level, [≤12]To age 12 or less, [≤16]To age 16, [≤18]To age 18, [FE]Further/higher education, [Ind]Independent, [Sup]Supported, [SD]Standard Deviation, [Min]Minimum value, [Max]Maximum value

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Table 61. Health status information about the 33 patients included in the economic analysis

Patient ID	Nurse Case manager type	HEALTH STATUS: Baseline			*Self Efficacy Raw data scores (means; 1-10 high scores better)	HEALTH RELATED QUALITY OF LIFE: EQ5D								
		Barthel (0-20, low is dependent)	CIT (0-28, ≥ 8 is problems)	GDS (0-4, ≥ 1 is depression)		Baseline (month 1)		Midpoint (month 5)		Endpoint (month 9)		Thermometer		
						Scores	UW	Scores	UW	Scores	UW	B	M	E
Site1N2P1	CM	14	9	0	28 (4.7)	22321	.26	22221	.59	23321	.15	25	50	20
Site1N2P2	CM	18	0	0	-	23322	.08	22312	.31	22312	.31	50	25	89
Site1N2P3	CM	20	12	0	52 (8.7)	11221	.76	11111	1	11211	.88	90	95	82
Site1N2P4	CM	18	0	1	22 (3.7)	21232	.09	22221	.59	11223	.25	50	40	45
Site1N2P7	CM	18	-	1	43 (7.2)	21222	.62	21231	.16	-	-	50	60	80
Site1N1P2	CNS	-	0	0	58 (9.7)	11111	1	11111	1	11111	1	80	80	85
Site1N1P3	CNS	20	0	4	40 (6.7)	21222	.62	21222	.62	11212	.81	60	50	70
Site1N1P4	CNS	20	-	0	43 (7.2)	11111	1	11111	1	11111	1	80	100	85
Site1N1P5	CNS	19	-	0	42 (7)	21222	.62	21221	.69	-	-	80	99	99
Site1N1P6	CNS	-	-	-	39 (6.5)	21222	.62	21211	.81	21221	.69	50	80	80
Site1N3P1	DN	18	6	0	50 (8.3)	21221	.69	21121	.73	11121	.80	45	60	80
Site1N4P3	NP	19	-	-	-	21223	.19	22322	.19	22221	.59	10	30	60
Site2N5P1	CM	20	0	4	40 (6.7)	11111	1	11111	1	11111	1	80	80	85
Site2N5P3	CM	20	6	4	51 (8.5)	21222	.62	21222	.62	11212	.81	60	50	70
Site2N5P4	CM	20	-	0	43 (7.2)	11111	1	11111	1	11111	1	80	100	85
Site2N5P5	CM	20	4	0	43 (7.2)	22222	.52	-	-	-	-	71	80	-
Site2N6P1	CM	19	-	0	42 (7)	21222	.62	21221	.69	-	-	80	99	99
Site2N6P2	CM	-	-	-	39 (6.5)	21222	.62	21211	.81	21221	.69	50	80	80
Site2N6P3	CM	14	9	0	28 (4.7)	22321	.26	22221	.59	23321	.15	25	50	20
Site2N6P4	CM	18	0	0	-	23322	.08	22312	.31	22312	.31	50	25	89
Site2N6P5	CM	20	12	0	52 (8.7)	11221	.76	11111	1	11211	.88	90	95	82
Site2N7P1	TNS	18	0	1	22 (3.7)	21232	.09	22221	.59	11223	.25	50	40	45
Site2N7P2	TNS	20	7	0	31 (5.2)	11111	1	-	-	-	-	80	80	-
Site2N7P4	TNS	19	-	0	42 (7)	21222	.62	21231	.16	-	-	50	60	80
Site2N7P5	TNS	20	7	0	49 (8.2)	11111	1	-	-	-	-	80	90	90
Site2N8P1	DN	18	6	0	50 (8.3)	21221	.69	21121	.73	11121	.80	45	60	80
Site2N8P5	DN	-	-	1	-	22222	.52	-	-	-	-	-	-	-
Site3N9P3	CM	20	7	1	40 (6.7)	22222	.52	-	-	-	-	60	-	-
Site3N9P5	CM	19	6	-	-	21223	.19	22322	.19	22221	.59	10	30	60
Site3N10P1	DN	-	-	-	-	21222	.62	21222	.62	11212	.81	60	50	70
Site3N10P2	DN	18	0	3	21 (3.5)	11111	1	11111	1	11111	1	80	80	85
Site3N10P3	DN	-	-	0	43 (7.2)	21221	.69	21121	.73	-	-	45	60	70
Site3N10P4	DN	20	-	0	53 (8.8)	11111	1	11111	1	-	-	80	80	85
Mean		18.8	4.6	0.7	41.0 (6.8)		.61		.67		.67	59.3	66.4	74.1
SD		1.63	4.25	1.33	9.99 (1.66)		.31		.29		.30	21.87	23.86	19.82
Min		14	0	0	21 (3.5)		.08		.16		.15	10	25	20
Max		20	12	4	58 (9.7)		1		1		1	90	100	99

*

Raw

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data used for 6 questions (each scored 1-10) and mean scores calculated, [CM]Community matron, [CNS]Cardiac Nurse Specialist, [DN]District Nurse, [NP]Nurse Practitioner, [TNS]Tissue Nurse Specialist, [Barthel]Barthel Index, [CIT]Kingshill Cognitive Test, [GDS]Geriatric Depression Scale, [Self Efficacy]Self Efficacy Scale, [UW]Utility Weight, [B]Baseline (month 1), [M]Mid-point (month 5), [E]End-point (month 9), [*SD*]Standard Deviation, [Min]Minimum value, [Max]Maximum value

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Table 62. Comparison of patients included in the economic analysis (*n*=33) with the full sample (*n*=51)

Variable	Value for full sample of 51 patients	Value for 33 patients in the economic analysis
Mean months on caseload prior to study	3.4	3.9
Gender, % male	39	48
Mean age in years	78	78
Mean number of co-morbidities	3.3	2.9
Mean number of medications	7.6	7.2
% live alone	57	61
% receiving disability benefits	78	82
Mean baseline CIT score	5.0	4.5
Mean baseline GDS score	7.8	7.3
Mean baseline Barthel score	18.9	18.8
Mean baseline EQ-5D thermometer score	0.63	0.61
Mean baseline EQ-5D utility score	59.1	59.0
Mean baseline Self Efficacy raw (mean) score	40.6 (7.3)	41.0 (6.9)

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Table 63. Services used by the 33 patients included in the economic analysis

Patient ID	Nurse Case manager type	NURSE CASE MANAGER USAGE						OTHER HEALTHCARE PROFESSIONAL USAGE: Total number of contacts (Mean/month)										
		Contacts			[a]Contact time/minutes			Nurses consultations					GP consultations				Other (including AHPs)	
		OH	IH	Total	[b]Total	Mean/ contact	Mean/ month	NS		[c]DN		PN	OH	IH	Out of hrs IH	Telephone calls	OH	IH
								OH	IH	OH	IH	OH						
Site1N2P1	*CM	1	41	42	2032	48.4	254	0	0	0	0	0	3 (.38)	2 (.25)	0	0	0	0
Site1N2P2	*CM	0	12	12	720	60	144	0	0	0	1 (.2)	1 (.2)	0	1 (.2)	0	0	0	0
Site1N2P3	*CM	0	33	33	1221	37	135.7	0	0	0	0	0	2 (.22)	0	0	0	2Po (.22)	0
Site1N2P4	*CM	0	14	14	518	37	57.6	0	2 (.22)	0	0	1 (.11)	2 (.22)	1 (.11)	0	0	0	0
Site1N2P7	*CM	0	8	8	480	60	68.6	0	1 (.14)	0	0	0	1 (.14)	0	0	0	0	6PT (.86), 2Phl (.29)
Site1N1P2	*CNS	9	0	9	158	17.6	17.6	0	0	0	0	0	4 (.44)	0	0	0	0	0
Site1N1P3	*CNS	8	0	8	161	20.1	20.1	0	0	0	0	0	7 (.88)	0	0	0	2Po (.25), 1Co (.13)	0
Site1N1P4	*CNS	7	0	7	103	14.7	12.9	0	0	0	0	0	2 (.25)	1 (.13)	0	0	3PT (.38)	0
Site1N1P5	*CNS	7	0	7	134	19.1	19.1	0	0	0	0	0	5 (.71)	0	0	0	0	0
Site1N1P6	*CNS	1	23	24	888	37	126.9	0	0	0	162 (23.14)	0	0	4 (.57)	0	0	0	0
Site1N3P1	DN	0	5	5	126	25.2	15.8	0	0	0	240 (30)	0	0	1 (.13)	4 (.5)	0	0	0
Site1N4P3	*NP	0	1	1	37	37	5.3	0	0	0	4 (.57)	0	0	1 (.14)	0	0	2Co (.33), 1SPU (.17)	1Opt (.17)
Site2N5P1	*CM	2	4	6	312	52	312	0	0	29 (3.22)	0	0	0	0	2 (.22)	1 (1)	7PRC (.78)	0
Site2N5P3	*CM	4	12	16	832	52	832	0	0	0	0	0	10 (1.11)	0	0	0	0	2PT (.22), 1OT (.11)
Site2N5P4	*CM	3	12	15	780	52	780	0	0	25 (2.78)	0	0	0	0	0	0	0	0
Site2N5P5	*CM	0	2	2	90	45	90	-	-	-	90 (22.5)	-	0	0	0	7 (2.3)	-	1OT (1)
Site2N6P1	*CM	1	4	5	260	52	260	0	0	32 (3.56)	0	0	0	0	0	0	0	3OT (.33)
Site2N6P2	*CM	7	8	15	780	52	780	0	0	0	0	0	0	17 (1.89)	0	0	0	0
Site2N6P3	*CM	7	4	11	572	52	572	0	0	68 (7.56)	0	0	0	0	0	4 (1.3)	0	22Pha (2.44), 3Po (.33)
Site2N6P4	*CM	8	8	16	832	52	832	0	0	67 (7.44)	0	0	0	36 (4)	0	0	0	36Pha (4)
Site2N6P5	*CM	2	2	4	208	52	208	0	0	0	0	0	36 (4)	0	0	0	0	0
Site2N7P1	TNS	0	2	2	54	27	54	2 (.22)	0	56 (6.22)	2 (.22)	0	0	0	0	0	0	0
Site2N7P2	TNS	3	0	3	135	45	67.5	4 (1)	-	-	-	-	3 (3)	0	0	0	-	-
Site2N7P4	TNS	10	1	11	242	22	242	1 (.11)	0	63 (7)	1 (.11)	0	0	0	2 (.22)	5 (2.5)	0	0
Site2N7P5	TNS	2	0	2	120	60	60	26 (2.89)	-	-	-	-	0	0	1 (1)	0	-	-
Site2N8P1	DN	15	5	20	240	12	240	0	0	32 (3.56)	0	0	3 (.33)	2 (.22)	1 (.11)	5 (2.5)	0	0
Site2N8P5	DN	0	4	4	80	20	80	-	-	-	64 (16)	-	0	3 (.75)	1 (.25)	0	-	-

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Site3N9P3	*CM	0	4	4	180	45	180	-	-	-	78 (19.5)	-	0	0	0	0	-	1OT (1)
Site3N9P5	*CM	1	5	6	312	52	312	0	0	49 (5.44)	0	0	5 (.56)	0	1 (.11)	0	0	0
Site3N10P1	DN	5	1	6	102	17	102	0	0	29 (3.22)	0	0	0	0	1 (.11)	0	0	1Opt (.11), 1Den (.11)
Site3N10P2	DN	1	12	13	221	17	221	0	0	34 (3.78)	0	0	0	0	1 (.11)	4 (2)	0	4PT (.44)
Site3N10P3	DN	0	1	1	12	12	12	0	0	67 (7.44)	0	86 (9.56)	2 (.22)	0	0	0	24PT (2.7)	9Pha (1)
Site3N10P4	DN	0	4	4	68	17	68	0	0	58 (6.44)	0	0	0	0	0	0	0	0
Mean		3.2	7.0	10.2	394.2	37.0	217.6	1.1 (.1)	.1 (.01)	21.8 (2.4)	20.7 (3.6)	3.1 (.35)	2.6 (.4)	2.1 (.25)	.4 (.1)	.79 (.4)	1.5 (.17)	3.1 (.4)
SD		3.87	9.39	9.14	429.02	16.41	252.39	4.77 (.55)	.42 (.048)	26.34 (2.93)	54.42 (8.51)	16.24 (1.80)	6.46 (.86)	6.80 (.76)	.87 (.20)	1.87 (.8)	4.69 (.54)	7.92 (.90)
Min		0	0	1	12	12	5.3	0	0	0	0	0	0	0	0	0	0	0
Max		15	41	42	2032	60	832	26 (2.89)	2 (.22)	68 (7.56)	240 (30)	86 (9.56)	36 (1.11)	36 (4)	4 (1)	7 (2.5)	24 (2.7)	36 (4)

*100% case management, [CM]Community matron, [CNS]Cardiac Nurse Specialist, [DN]District Nurse, [NP]Nurse Practitioner, [TNS]Tissue Nurse Specialist, [OH]Outside home, [IH]Inside home, [a]Face-to-face contact time (no extra travel time accounted for in IH visits), [b]Contact time calculated based on average length of time recorded for various sessions (no distinction was given between OH and IH visits), [NS]Nurse Specialist, [c]Includes IH visits from Palliative Care Team, [PN]Practice Nurse, [GP]General Practitioner, [hrs]hours, [AHP]Allied Health Professional, [Po]Podiatrist/Chiropodist, [Co]Counsellor, [PT]Physiotherapist, [SPU]Sensory Perception Unit, [PRC]Pulmonary Rehabilitation Clinic, [Phl]Phlebotomist, [Opt]Optician, [OT]Occupational therapist, [Pha]Pharmacist delivery, [Den]Dentist, [SD]Standard Deviation [Min]Minimum value, [Max]Maximum value

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Table 64. Services used by the 33 patients included in the economic analysis

Patient ID	Nurse Case man-ager type	NHS USAGE: Total (Mean/month)						SOCIAL SERVICES				SOCIAL CARE: Paid care assistance		
		*Pathology tests	Hospital outpatients clinics	A&E visits	No. of hospital days		No. days in hospice	CARELINE			MEALS ON WHEELS	Total hours	Mean hrs/ month	Payer
					Planned	Unplanned		Subs mths	No. used	Payer	Subs mths (Payer)			
Site1N2P1	CM	3BT (.33), 1UT (.11)	2C (.25), 3RM (.38), 1Echo (.13)	0	0	9Pn (1.13), 5COPD (.63)	0	8	0	NHS/ SS	0	-	-	-
Site1N2P2	CM	-	1RM (.2)	3 (.6)	0	15COPD (3)	0	5	6	NHS/ SS	0	24	12	NHS/ SS all
Site1N2P3	CM	9BS (1)	1GM (.11), 2DMed (.22)	0	0	0	0	9	0	NHS/ SS	0	-	-	-
Site1N2P4	CM	2BT (.22)	0	1 (.11)	0	0	0	9	1	NHS/ SS	0	live in (6048)	9 mths (672)	NHS/ SS all
Site1N2P7	CM	1BT (.11)	1C (.14), 1Rh (.14), 1Or (.14), 1U (.14)	0	0	0	0	7	0	NHS/ SS	0	-	-	-
Site1N1P2	CNS	9BT (1)	2C (.22), 2AC (.22)	0	0	3TIA (.33)	0	0	0		0	-	-	-
Site1N1P3	CNS	8BT (.89)	0	0	0	0	0	0	0		0	-	-	-
Site1N1P4	CNS	7BT (.78)	1C (.13), 2U (.25)	0	0	0	0	0	0		0	-	-	-
Site1N1P5	CNS	6BT (.67)	1C (.14), 2AC (.29)	0	0	0	0	7	0	NHS/ SS	0	-	-	-
Site1N1P6	CNS	7BT (.78)	12TV (1.71)	0	0	40HF (5.71)	0	7	3	NHS/ SS	0	-	-	-
Site1N3P1	DN	1BT (.11)	1VS (.13), 1TV (.13)	1 (.13)	0	0	0	8	6	NHS/ SS	0	-	-	-
Site1N4P3	NP	1BT (.11), 1UT (.11)	1VAU (.14)	0	0	0	0	0	0		0	-	-	-
Site2N5P1	CM	9BT (1)	1RM (.11)	0	0	1Pn (.11)	0	0	0		0	-	-	-
Site2N5P3	CM	9BT (1)	2C (.22), 1VS (.11), 2DMed (.22)	0	0	0	0	0	0		0	-	-	-
Site2N5P4	CM	7BT (.78)	1Oph (.11), 1VS (.11), 1A (.11)	0	3PMF (.33), 1Ca (.11)	0	0	0	0		0	468	52	Pt some
Site2N5P5	CM	7BT (1.4)	1C (.5), 1VS (.5)	0	0	0	0	0	0		0	-	-	-
Site2N6P1	CM	6BT (.75)	2C (.22), 1VS (.11), 2DMed (.22)	0	3HI (.33), 1Obs (.11)	5Inv (5)	0	0	0		0	-	-	-
Site2N6P2	CM	7BT (.78)	1GM (.11), 1C (.11)	0	0	0	0	9	0	NHS/ SS	0	-	-	-
Site2N6P3	CM	2BT (.22), 1UT (.11)	4RM (.44), 2Psy (.22)	0	13Lob (1.44)	4COPD (.44)	0	0	0		0	-	-	-
Site2N6P4	CM	-	2C (.22), 1Oph (.11), 2DMed (.22)	0	1.37Ca (.15), 2.63Com (.29)	11CHD (1.22)	0	0	0		0	24	12	Pt some
Site2N6P5	CM	9BS (1)	1RM (.11), 3C (.33), 1Oph (.11), 1VS (.11), 1GM (.11)	0	5VS (.56)	12CPain (1.33)	0	9	0	NHS/ SS	0	24	12	Pt some
Site2N7P1	TNS	3BT (.33)	1RM (.11), 1VS (.11)	0	0	0	0	0	0		0	48	12	Pt some
Site2N7P2	TNS	0	1C (.5), 1VS (.5)	-	-	-	-	0	0		1 (SS)	-	-	-

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Site2N7P4	TNS	8BT (.89)	1C (.11), 1VS (.11)	0	0	0	0	0	0		0	-	-	-
Site2N7P5	TNS	1BT (.11), 1BP (.11), 1UT (.11)	1C (.33), 2VS (.66)	-	-	-	-	0	0		0	-	-	-
Site2N8P1	DN	8BT (.89)	2C (.22), 1Rh (.11), 1GM (.11)	0	0	0	0	0	0		0	-	-	-
Site2N8P5	DN	3BT (.75), 3BP (.75), 3UT (.75)	4U (1)	-	-	-	-	0	0		0	-	-	-
Site3N9P3	CM	4BT (.44), 2UT (.22)	-	-	-	-	-	0	0		0	112	28	SS all
Site3N9P5	CM	6BT (.67)	1GM (.11)	0	0	12COPD (1.33), 4Inv (.44)	0	9	0	NHS/ SS	2 (SS)	-	-	-
Site3N10P1	DN	5BT (.56)	0	0	0	0	0	0	0	NHS/ SS	0	-	-	-
Site3N10P2	DN	1UT (.11)	3Oph (.33), 1DMed (.11), 1Or (.11)	0	2Ca (.22)	6Falls (.67)	0	9	0	NHS/ SS	0	12	12	Pt some
Site3N10P3	DN	8BS (.89)	1C (.11), 1N (.11)	0	0	2Falls (.22), 3Obs (.33), 3TIA (.33)	0	9	0	NHS/ SS	0	12	12	Pt some
Site3N10P4	DN	2BT (.22), 1BS (.11)	2DMed (.22), 1GM (.11)	0	2Obs (.22)	4CRe (.44)	1 (.11)	0	0	NHS/ SS	0	96	12	Pt some
Mean		5.6 (.68)	3.2 (.47)	.2 (.03)	1.2 (.13)	4.8 (.78)	.03 (.004)	3.2	.5		.09	686.8	83.6	
SD		2.91 (.452)	2.43 (.375)	.60 (.114)	2.74 (.303)	8.54 (1.465)	.185 (.020)	4.08	1.52		.384	1888.75	207.15	
Min		0	0	0	0	0	0	0	0		0	12	12	
Max		9 (2.25)	12 (1.71)	3 (.6)	13 (1.44)	40 (5.71)	1 (.11)	9	6		2	6048	672	

[*]Only BT and UT used in costing, [CM]Community matron, [CNS]Cardiac Nurse Specialist, [DN]District Nurse, [NP]Nurse Practitioner, [TNS]Tissue Nurse Specialist, [BT]Blood Test, [UT]Urine Test, [BS]Blood Sugar, [BP]Blood Pressure, [NHS]National Health Service, [A]Audiology, [AC]Anti-coagulation clinic, [C]Cardiology, [DMed]Diabetic Medicine, [Echo]Echocardiogram, [GM]Geriatric Medicine, [N]Neurology, [Oph]Ophthalmology, [Or]Orthopaedics, [Psy]Psychiatrist, [RM]Respiratory Medicine, [Rh]Rheumatology, [TV]Tissue Viability clinic, [U]Urology, [VS]Vascular Surgery, [VAU]Visual Aids Unit, [A&E]Accident and Emergency, [No.]Number, [Ca]Cataract surgery, [Com]Complications, [HI]Head Injury, [Lob]Lobectomy, [Obs]Observations, [PMF]Pacemaker Fitting, [CPain]Chest Pain, [COPD]Chronic Obstructive Pulmonary Disease exacerbation, [CHD]Coronary Heart Disease exacerbation, [CRe]Eyelid Cyst Removal, [HF]Heart Failure, [Inv]Investigations, [Pn]Pneumonia, [TIA]Transient Ischaemic Attack, [Subs mths]Months of subscription to service, [mths]months, [SS]Social Service, [Pt]Patient, [SD]Standard Deviation [Min]Minimum value, [Max]Maximum value

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Table 65. Services used by the 33 patients included in the economic analysis

Patient ID	Nurse Case man-ager type	UNPAID ASSISTANCE												PRIVATE PAID ASSISTANCE		
		CARER INFORMATION										UNPAID INFORMAL CARE	VOLUNTARY SECTOR HELP (all Age Concern)	Paid cleaner	Private health consultations	Transport to consultation payer
		Avai-lable	Live in	Relati-onship	Age	Sex	Health probs	CSI		Hours per day carer spends on:				Mean hrs/ month		
								B	E	House-hold tasks	Perso-nal care	Mean hrs/ month				
Site1N2P1	CM	Yes	full time	Spouse	62	F	No	2	0	-	-	-	-	-	0	Pt all
Site1N2P2	CM											224	1 mth	56	0	SS all
Site1N2P3	CM	Yes	part time	OF	66	F	No	4	4	-	-	-	-	-	0	-
Site1N2P4	CM											-	-		0	SS all
Site1N2P7	CM											-	-	240	0	-
Site1N1P2	CNS											-	-	-	6	-
Site1N1P3	CNS											-	-	72	0	-
Site1N1P4	*CNS	-	-	-	-	-	-	-	-	-	-	-	-	-	0	-
Site1N1P5	*CNS	-	-	-	-	-	-	-	-	-	-	-	Yes (no details)	-	0	-
Site1N1P6	CNS											-	28Weekly shop (7mths)	72	0	SS some
Site1N3P1	DN											-	-	-	0	-
Site1N4P3	*NP	-	-	-	-	-	-	-	-	-	-	-	-	72	0	-
Site2N5P1	CM	Yes	full time	Spouse	67	F	Minor	2	3	1-2	1-2	-	-	-	0	Pt all
Site2N5P3	CM	Yes	full time	Spouse	71	F	Minor	7	7	5-6	3-4	-	-	-	0	Pt all
Site2N5P4	CM											-	-	-	0	Pt all
Site2N5P5	CM											-	-	-	0	SS some
Site2N6P1	CM											-	-	-	0	SS all
Site2N6P2	CM	Yes	full time	Spouse	76	F	Serious	10	11	3-4	1-2	12	31Day Centre (7 mths)	-	0	SS all
Site2N6P3	CM											-	-	-	0	Pt all
Site2N6P4	CM											-	-	-	0	SS all
Site2N6P5	*CM	-	-	-	-	-	-	-	-	-	-	80	-	-	0	Pt all
Site2N7P1	TNS											-	-	-	0	Pt all
Site2N7P2	*TNS	-	-	-	-	-	-	-	-	-	-	-	-	-	0	Pt all
Site2N7P4	TNS											-	-	-	0	Pt all
Site2N7P5	*TNS	-	-	-	-	-	-	-	-	-	-	-	-	-	0	Pt all
Site2N8P1	DN	Yes	full time	Spouse	81	F	Minor	6	7	1-2	3-4	-	36Day Centre (9 mths)	-	0	SS some
Site2N8P5	DN											-	-	-	0	Pt all

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Site3N9P3	CM											-	-	-	0	SS some
Site3N9P5	CM											12	-	-	0	-
Site3N10P1	DN	Yes	full time	Spouse	60	F	Serious	12	10	1-2	20	live in/9 mths (672)	-	-	0	-
Site3N10P2	DN											-	-	-	0	Pt all
Site3N10P3	DN											-	-	-	0	Pt all
Site3N10P4	DN	Yes	full time	Spouse	79	M	Serious	4	4	1-2	1-2	-	-	-	0	SS some
Mean					70.3			5.9	5.8	[1]2.5	[1]5.3	200		102.4	0.18	
SD					7.81			3.64	3.69	1.67	7.29	277.69		77.23	1.04	
Min					60			2	0	1.5	1.5	12		56	0	
Max					81			12	11	5.5	20	672		240	6	

*Where patient indicated not living alone (Table ECON3), but carer did not consent to participate in study, [1]values calculated from mid-point of range, [CM]Community matron, [CNS]Cardiac Nurse Specialist, [DN]District Nurse, [NP]Nurse Practitioner, [TNS]Tissue Nurse Specialist, [OF]Other family, [M]Male, [F]Female, [probs]problems, [CSI]Carer Strain Index, [B]Baseline (month 1), [E]Endpoint (month 9), [hrs]hours, [mths]months, [Pt]Patient, [SS]Social Services, [SD]Standard Deviation [Min]Minimum value, [Max]Maximum value

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Table 66. Costs of service provision for 33 case managed patients

Patient ID	Nurse Case manager type	[a]Case manager usage costs/ mth (£)	NHS RESOURCE USE: Costs (£) per month												SS RESOURCE USE: Costs (£) per month				[g]TOTAL COSTS PER MONTH (£)	TOTAL COSTS PER MONTH (£) exc. Nurse Case Manager costs
			[b]Nurse consultations	[c]GP consultations	Other (inc. AHP)	[d]Pathology tests	[e]Hospital outpatients clinics		A & E visits	Hospital stays			Hospice stays	[f]TOTAL	CL	MOW	Social care assistance	TOTAL		
							[f]MDT	Non-MDT		Planned	Unplanned	Total								
Site1N2P1	CM	385	0	28	0	1	96	100	0	0	493	493	0	618	17	0	0	17	1020	635
Site1N2P2	CM	219	7	12	0	0	27	30	67	0	750	750	0	863	17	0	288	305	1387	1168
Site1N2P3	CM	207	0	8	2	0	69	57	0	0	0	0	0	79	17	0	0	17	303	96
Site1N2P4	CM	88	7	14	0	1	0	0	12	0	0	0	0	34	17	0	2587	2604	2726	2638
Site1N2P7	CM	105	4	5	48	0	70	68	0	0	0	0	0	127	17	0	0	17	249	144
Site1N1P2	CNS	17	0	16	0	3	36	33	0	0	90	90	0	145	0	0	0	0	162	145
Site1N1P3	CNS	19	0	32	11	3	0	0	0	0	0	0	0	46	0	0	0	0	65	46
Site1N1P4	CNS	12	0	17	13	2	48	43	0	0	0	0	0	80	0	0	0	0	92	80
Site1N1P5	CNS	18	0	26	0	2	25	24	0	0	0	0	0	53	17	0	0	17	88	70
Site1N1P6	CNS	172	588	33	0	3	157	157	0	0	3345	3345	0	4126	17	0	0	17	4315	4143
Site1N3P1	DN	20	762	37	0	0	28	27	14	0	0	0	0	841	17	0	0	17	878	858
Site1N4P3	NP	8	14	8	37	1	10	9	0	0	0	0	0	70	0	0	0	0	78	70
Site2N5P1	CM	711	42	35	42	3	15	17	0	0	33	33	0	170	0	0	0	0	881	170
Site2N5P3	CM	1190	0	40	16	3	101	74	0	0	0	0	0	160	0	0	0	0	1350	160
Site2N5P4	CM	1130	36	0	0	2	48	43	0	569	0	569	0	655	0	0	1248	1248	3033	1903
Site2N5P5	CM	137	572	51	49	4	134	124	0	0	0	0	0	810	0	0	0	0	947	810
Site2N6P1	CM	377	46	0	16	2	101	74	0	279	2512	2791	0	2956	0	0	0	0	3333	2956
Site2N6P2	CM	1052	0	110	0	2	29	39	0	0	0	0	0	141	17	0	0	17	1210	158
Site2N6P3	CM	736	98	29	95	1	87	116	0	780	110	890	0	1200	0	0	0	0	1936	1200
Site2N6P4	CM	1110	97	232	144	0	100	71	0	1464	393	1856	0	2429	0	0	288	288	3827	2717
Site2N6P5	CM	278	0	144	0	0	102	107	0	303	491	794	0	1040	17	0	288	305	1623	1345
Site2N7P1	TNS	74	89	0	0	1	29	29	0	0	0	0	0	119	0	0	288	288	481	407
Site2N7P2	TNS	65	15	108	0	0	134	124	0	0	0	0	0	257	0	38	0	38	360	295
Site2N7P4	TNS	243	96	68	0	3	29	27	0	0	0	0	0	196	0	0	0	0	439	196
Site2N7P5	TNS	58	42	58	0	1	129	119	0	0	0	0	0	230	0	0	0	0	288	230
Site2N8P1	DN	230	46	86	0	3	58	71	0	0	0	0	0	193	0	0	0	0	423	193
Site2N8P5	DN	99	406	58	0	5	118	105	0	0	0	0	0	587	0	0	0	0	686	587

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Site3N9P3	CM	274	495	0	49	2	0	0	0	0	0	0	0	546	0	0	672	672	1492	1218
Site3N9P5	CM	456	71	27	0	2	14	24	0	0	554	554	0	668	17	38	0	55	1179	723
Site3N10P1	DN	95	42	6	13	2	0	0	0	0	0	0	0	63	0	0	0	0	158	63
Site3N10P2	DN	268	49	50	22	0	79	55	0	323	174	496	0	696	17	0	288	305	1269	1001
Site3N10P3	DN	15	202	8	128	0	42	32	0	0	320	320	0	700	17	0	288	305	1020	1005
Site3N10P4	DN	84	84	0	0	1	69	57	0	125	142	267	56	477	0	0	288	288	849	765
Mean		302	118	41	21	1.6	60	56	2.81	116	285	401	1.7	648	6.7	2.3	198	207	1156	854
SD		358	202	49	37	1.3	46	43	11.9	302	718	798	9.7	900	8.4	9.2	500	500	1125	995
Min		8	0	0	0	0	0	0	0	0	0	0	0	34	0	0	0	0	65	46
Max		1190	762	232	144	5	157	157	67	1464	3345	3345	56	4126	17	38	2587	2604	4315	4143

based on data in Curtis, 2008, including overheads and qualifications; and DH 2008, All calculations rounded to the nearest £, [NHS]National Health Service, [SS]Social Services, [a]calculated per hour, pro rata for home (IH) and clinic (OH) visits, [b]calculated per visit, pro rata for IH and OH visits for nurse specialist, district nurse and practice nurse, [GP]General Practitioner, [c]includes costs for surgery, home (normal and out of hours) and telephone consultations, [d]only used blood and urine tests in calculation, [inc.]including, [AHP]allied health professional, [e]calculated based on means of first and follow up attendance costs derived from National Reference Costs Index for specific outpatients clinics which could be consultant or non-consultant led with multidisciplinary team (MDT) input or without (non-MDT), [A&E]Accident and Emergency, [f]only MDT costs considered in total overall costs, [CL]Careline, [MOW]Meals on wheels, [g]Total cost = Nurse case manager costs + Total NHS resource use + Total SS resource use, [exc.]excluding [SD]Standard Deviation [Min]Minimum value, [Max]Maximum value

7.4 Demographic and health factors associated with resource use and costs

Differences between characteristics of patients between types of nurse case manager and site were explored using chi-square, t tests and Mann Whitney U tests. Backwards and forwards stepwise regression was used to explore: the patient characteristics associated with total patient costs and nurse case manager mean monthly time input and patients' utilisation of other services; the patient and service delivery factors that predict hospitalisations. Independent variables considered in each analysis were baseline: age, gender, number of co-morbidities, number of medications, and scores for cognition (CIT), depression (GDS), dependency (Barthel), health related quality of life (EQ 5D index and thermometer), and self efficacy. Study site type (city, coastal, shore) was also included. Scattered missing data meant some variables had to be left out of some models.

7.4.1 Findings

a) Comparison of characteristics of patients of community matrons with those of patients of other types of nurse case manager

The patients of community matrons were significantly older and had significantly more prescribed medications than those of the other types of nurse case manager (specialist nurses, district nurses, nurse practitioner). No significant differences were found between patients of community matrons and other nurse case managers for: gender; live alone; number of co-morbidities; baseline scores for CIT, GDS, Barthel, EQ5D index, EQ5D thermometer, self efficacy (Table 67).

The analysis was repeated with the Cardiac Nurse Specialist treated as a community matron because, unlike the other nurse specialists and DNs in the study, she was spending 100% of her time on case management, and had a relatively small case load. In these tests, the only significant difference in patient characteristics between the exclusive case management group and other nurse case managers was with respect to the number of medications: patients of exclusive case managers had more (data not shown).

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Table 67. Comparison of the characteristics of patients managed by community matrons and other nurse case managers at baseline

Characteristic		Community matron	Other case manager	Significance
Gender	Male	9	7	Chi Square
	Female	7	10	ns
	Total	16	17	
Lives alone	No	5	8	Chi Square
	Yes	11	9	ns
	Total	16	17	
Age (years)	Mean	81.1	74.9	t test
	SD	9.1	7.9	p= .034
	n	16	17	
Number of co-morbidities	Mean	3.2	2.7	t test
	SD	2.1	0.95	ns
	n	16	17	
Number of medications	Mean	8.9	5.6	t test
	SD	3.9	3.2	p= .014
	n	16	17	
EQ 5D Utility score	Mean	.50	.70	t test
	SD	.31	.28	p= .054
	n	16	17	
EQ 5D thermometer	Mean	56.7	60.9	t test
	SD	23.8	20.4	ns
	n	16	16	
Barthel dependency score	Mean	18.5	19.1	t test
	SD	2.0	.90	ns
	n	15	12	
Kingshill cognitive score	Mean	5.4	3.3	t test
	SD	4.6	3.5	ns
	n	12	8	
Geriatric Depression score	Mean	.79	.64	t test
	SD	1.4	1.28	ns
	n	14	14	
Self Efficacy score	Mean	6.7	7.0	t test
	SD	1.6	1.8	ns
	n	13	14	

Table Key: SD, Standard Deviation; n, number; ns, not significant

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b) Comparison of characteristics of patients by site

No significant differences were found between the characteristics of patients (age; gender; live alone; number of comorbidities; number of medications; baseline scores for CIT, GDS, Barthel, EQ5D index, EQ5D thermometer, self efficacy) recruited to the study between the three sites. However, given the small sample size (n=33) distributed amongst the three sites, this is not surprising (data not shown).

c) Predictors of patient costs

Results of bivariate tests of association between total cost per month and baseline patient characteristics are shown in Table 68. Higher total costs were significantly associated with living alone, number of co-morbidities, number of medications, and being case managed by a community matron.

Table 68. Bivariate associations between total costs per month and baseline characteristics of patients

Characteristic		n	Mean (£)	SD	Significance
Gender	Male	16	1174.19	1107.18	t test: ns
	Female	17	1138.82	1175.04	
Live alone	No	13	647.69	535.67	t test: p= .015
	Yes	20	1486.35	1287.69	
Community matron		16	1656.00	1051.46	t test: p= .011
Other nurse case manager		17	685.35	1004.38	
Age		33	77.9	8.95	Pearson correlation: ns
Number of co-morbidities		33	2.9	1.11	Pearson correlation: p=.022, r=.402
Number of medications		33	7.2	3.87	Pearson correlation: p=.028, r=.382

Key: SD, Standard Deviation; n, number; ns, not significant.

[Footnote to table: There were no significant associations (Pearson correlations) between total costs per month and EQ 5D utility weight, EQ 5D thermometer score, Barthel dependency score, Kingshill cognitive score, Geriatric Depression Scale, Self Efficacy score.]

Backwards and forwards stepwise linear regression was used to explore the patient characteristics associated with total cost per patient per month. Several variables (number of co-morbidities; baseline scores for CIT, GDS, Barthel, EQ5D index, EQ5D thermometer, self efficacy) had to be dropped from the analysis because scattered missing data reduced the size of the sample. The independent variables used in the analysis were: age; gender, live alone; number of medications; site; nurse case manager model (community matron vs other). Site was included using a dummy variable to signify city, coast or shire. The results show (Table 69 Model 1) that monthly patient total cost is positively and significantly associated with being managed by a community matron, which

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raised monthly costs on average by around £971, p =.01. When forced into the final regression model, living alone was also found to be positively associated with monthly total cost (Table 70, Model 2). Management by a community matron added £861 to total monthly cost (p=.019), and living alone added a further £696 (p=.059). However, it should be noted that the 95% confidence intervals around both these points are large.

Similar results (not shown) emerged when the modelling was repeated with the CNS patients included in the same group as those of the community matrons, although the R2 (explained variations) were slightly lower (156 vs .192 and .252 vs .284 for Models 1 and 2 respectively).

Table 69. Results of backwards and forwards stepwise linear regression Dependent variable: Total cost

	Variable	Beta	Std Error	p	95% CI for Beta	R2
Model 1	Constant	685.35	249.19	.01	177.13 to 1193.58	.192
	Community matron	970.65	357.87	.011	240.77 to 1700.53	
Model 2 (forced)	Constant	316.71	303.62	.305	-303.37 to -936.78	.284
	Community matron	860.57	347.05	.019	151.80 to 1569.33	
	Lives alone	696.33	354.97	.059	-28.607 to-1421.27	

d) Predictors of care manager time input

Results of bivariate tests of association between nurse case manager time per patient per month (mean number of minutes) and baseline patient characteristics are shown in Table 70. The only factor that correlates significantly with time spent is having a community matron as a nurse case manager.

Backwards and forwards stepwise linear regression was used to explore the patient characteristics associated with nurse case manager time per patient per month (mean number of minutes). Several variables (number of co-morbidities; baseline scores for CIT, GDS, Barthel, EQ5D index, EQ5D thermometer, self efficacy) had to be dropped from the analysis because scattered missing data reduced the size of the sample. The independent variables used in the analysis were: age; gender, live alone; number of medications; site; nurse case manager model (community matron vs other). The results (Table 72, Model 1) show that mean monthly nurse case manager time spent with patients is positively and significantly associated with being managed by a community matron, (which raised monthly time spent on average by around 240 minutes, p=.001), and being located in the coastal site #2 (which raised monthly time spent on average, compared to a non coastal site, by around 210 minutes (p=.003). However, it should be noted that the 95% confidence intervals around both these estimates are wide.

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Table 70. Bivariate associations between nurse case manager time per patient per month (minutes) and baseline characteristics of patients

Characteristic		n	Mean (£)	SD	Significance
Gender	Male	16	272.59	274.47	t test: ns
	Female	17	165.92	225.62	
Live alone	No	13	227.75	275.80	t test: ns
	Yes	20	211.07	243.16	
Community matron		16	363.62	291.05	t test: p= .002
Other nurse case manager		17	80.25	81.32	

Key: SD, Standard Deviation; n, number; ns, not significant

[Foot note to table 71: There were no significant associations (Pearson correlations) between nurse manager time per patient per month and age, number of comorbidities, number of medications, EQ 5D utility weight, EQ 5D thermometer score, Barthel dependency score, Kingshill cognitive score, Geriatric Depression Scale, Self Efficacy, days in hospital.]

The regression analysis was repeated with the CNS patients included in the same group as those of the community matrons (Table 71, Model 2). The significant predictors of nurse case manager time spent were: being managed by a community matron, and living in the city site #1 (lower time spent compared to coast / shire sites).

Table 71. Results of backwards and forwards stepwise linear regression. Dependent variable: Nurse case manager time per patient per month (minutes)

	Variable	Beta	Std Error	p	95% CI for Beta	R2
Model 1	Constant	5.53	50.56	.914	-97.73 to 108.79	.497
	Coast[1]	211.70	66.13	.003	76.64 to 346.76	
	Community matron	239.01	65.89	.001	104.44 to 373.57	
Model 2*	Constant	149.95	55.98	.012	35.61 to 264.28	.472
	City[2]	-315.88	72.08	<.001	-463.09 to -168.66	
	Community matron*	286.88	72.08	<.001	139.66 to 434.09	

Key: CI, Confidence Intervals. [1.] Coast – significantly more time spent than city / shire. [2.] City – significantly less time spent than coast / shire. * includes cardiac nurse specialist who only does case management in the community matron group.

e) Associations between nurse case manager input and use of other services

Since nurse case manager time is a major component of total costs (Table 66), we explored whether nurse case manager input is a substitute for use of other services. Associations between mean monthly minutes spent by nurse case

manager and patients' utilisation of other community services (including nurse, GP, other health professionals, tests by community matrons, A&E visits, and outpatient appointments) were calculated, but no significant correlations were identified. Higher input from nurse case managers is thus not associated with either less or more demand for other community services. Data limitations meant we could not include voluntary sector help or informal caring in the analysis.

f) Predictors of hospitalisations

There was a strong positive correlation between days in hospital and total costs (Pearson $r = .677$; $p<.001$; $n=29$). Since hospital costs are a major component of total costs (Table 66), we investigated patient and service delivery factors that might predict hospitalisation. The dependent variable was number of days (planned and unplanned) spent in hospital (monthly mean). The independent variables entered into the regression model were: site, nurse case manager model (community matron vs other); number of medications; age; gender; live alone; EQ5D baseline thermometer value. None of these variables were significant. Other potential predictor variables relating to baseline health of the patients could not be included because missing data would have reduced the sample size, and due to apparent ceiling effects (Barthel and EQ5D index). Hospitalisation episodes appear unrelated to nurse case manager model and patient characteristics.

7.5 Conclusion

The economics analysis is done on a subsample (n=33) of the 51 patients recruited to the study and there was an element of gate-keeping by the nurse case managers who could be approached to participate in the study. Case management when it is carried out by nurses who exclusively focus on it (community matrons) is expensive – whether you calculate cost (as we have done) by top down methods (nurse costs divided by caseload), or by bottom up methods (careful collection of resource use and costing of services used by patients). Costs seem to be related to caseloads. The issue is whether extra time and resources (higher intensity input) is good value for money, the next chapter considers the patients and carers' understanding of nurse case management.

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8 Patient experiences of case management

8.1 Introduction

This chapter by focusing on the patient as the recipient of nurse case management addresses the research question that asked

- What is the impact of nurses' contribution to the experiences of patients?

The review of the literature on nurse case management consistently demonstrated that nursing interventions are valued and well received by patients regardless of model, range of interventions or context of care and this was corroborated by the case study findings. This chapter presents, from the patients' perspective, what contributed to patient satisfaction, and how the components of the nurse case manager role were defined. We consider what elements of the role were evident in all the models of care, the perceived benefits, and outcomes and negative consequences of being a patient in receipt of nurse led case management.

Discussion of how the nurse case manager and their particular contribution helped patients to achieve a better quality of life is grouped around three recurrent themes. These were, the nurse case manager as clinical expert, as support and as intermediary. Threaded through these responses was the importance of how much time the nurses gave to the patient and the importance of continuity of care.

8.2 The nurse case manager as clinical expert

All the patients either wanted their health and social situation to improve or, perhaps more importantly and realistically, not deteriorate. In addition to their experiences of different diseases, many of the patients in the study were in pain and/or experienced fatigue. In the monthly interviews many described a state of health that could fluctuate from day to day. A dominant theme of the patients' narratives was how much they valued the nurse case manager's knowledge and ability to improve their health and well-being. Patients defined this expertise as the ability to understand their particular health problems/symptoms and to recognise when further interventions were necessary; the ability to help them manage their condition and understand what was and was not possible, and being in possession of skills in diagnosis and prescribing that allowed them to substitute for doctors.

The patients of clinical nurse specialists and the community matrons with a special interest in COPD provided specific examples of how their leg ulcers, breathing, and medication management had improved over the nine months of care. Patients talked about things being 'sorted out', regaining function, in ways they had not thought possible, and learning more about how to manage their condition themselves:

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"*I think she is going to send me on some kind of course, which will help with this breathing problem. The main thing is my breathing and she seems to be a real expert which is great, to tell you the truth I think she probably knows more than my GP who can be pretty vague and rushing me sometimes*." Clinical Nurse Specialist Patient

(Reviewing her health at the nine month point) "*I'm better definitely, I was frightened of doing too much, and making my heart worse, but now I do a lot more around the house and go to the shops*." Clinical nurse specialist patient

Over the nine months, nurses' expertise and advice were credited as giving patients the confidence to do more (e.g. manage exacerbations, leaving the house, going on outings). Whilst some patients could identify when a nurse's intervention had avoided the need for a hospital admission or had improved the healing of a previously intractable wound, for the majority, changes were often small but tangible improvements: such as being able to manage injections themselves, use a nebuliser, walk greater distances, make a cup of tea, or their partner/carer being less anxious.

A few patients commented that the nurses' input had helped them to understand better their limitations, to be realistic and "tell it like it is", and when they were approaching the end stages of their condition. The realisation that their overall health was not going to improve meant that patients saw the nurses' expertise as helping them to manage rather than achieve any particular improvements:

"*They keep this wrecked old body going and I'm grateful for that, even if I'm a grumpy old bugger sometimes*." Community matron patient

This was also important when patients and their carers had to make decisions about whether to have further treatment or not. There were examples of patients with heart failure, renal failure, and end stage COPD who, following discussions with their case manager (community matron or CNS) about their health decided to decline further in- patient care. In one example, discussions between the community matron, the patient, and the carer about a patient's prognosis led to the carer giving up her part-time job to have more time with him.

For patients with multiple health problems and complicated drug regimes the nurses helped them to interpret the significance of symptoms (e.g. tachycardia, oedema, breathlessness) and worked with them to find strategies that could ameliorate them. Nurses could also change and adjust doses and drug regimes as symptoms and situations changed. This was an area where the clinical nurse specialists and community matrons as independent prescribers were recognised as having a particular expertise. There were examples over the nine months of community matrons and clinical nurse specialists bringing forward and initiating hospital appointments with surgeons and physicians, for example, asking their GP to refer a patient for angioplasty or suggesting a rheumatology appointment because of a patient's increasing pain. Equally valued, however, was when the patients talked about delaying talking to or 'not bothering' their GP, because they could now ask the case manager for advice. This was true for the district nurse, community matron, and clinical nurse specialists. Patients saw the nurse case manager as replacing and not supplementing their GP for aspects of their care.

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This element of the nurses' expertise directly informed the second theme of the nurse case manager as a source of support.

8.3 The nurse case manager as resource and support

Care provision and care co-ordination are core case management activities and patients presented this work in terms of the continuity of support and services they received from and through their case manager. Patients emphasised the importance of their ongoing relationship with the case manager. They defined the support that nurses offered by: their accessibility, how well the nurse knew them and understood their situation, the frequency of contact and the extra resources and services they obtained on their behalf.

Patients were not always clear how this had been achieved, and for many it had been a gradual process of receiving help and accepting services offered. Across the three models of nurse case management patients did not appear to have a particular expectation of what a nurse case manager should do, but they were able to describe what the impact had been.

The example of one patient who had been in contact with many different health services for a long time illustrates the range of support that patients received over time through having a nurse case manager. Following the involvement of the district nurse in his care, this man had had a ramp installed enabling him to get into his garden, domiciliary visits from a dentist, a podiatrist and a physiotherapist and an assessment from a low vision specialist. The couple then accepted a 'sitting service' so that his wife could go out, on the understanding the sitter would not do any cleaning (as this would be perceived to be an insult). This patient saw the cumulative impact of these interventions as '*making their lives easier*'.

"*I can't fault it. The nurses are all wonderful and [case manager] has done a lot to make our lives easier. I don't know exactly how she has done it, but since we first met her a lot more seems to have happened and we seem to be getting more support from all kinds of people. I think the nurse seems to be helping my wife too, and that makes me feel quite happy*." District nurse patient

Others described how a case manager's interventions had resulted in speedier access to a range of services:

"*The Community matron made a big difference to me. I wouldn't have had the cataracts sorted so quickly or my new hearing aids without her*." Community matron patient

The care home residents had the least understanding of why they had a case manager, but two of the three of them made a particular point about how it was good to have a nurse take an interest in their health and where it could be helped or improved:

"*She was very nice, she came and talked to me a lot and it was good to be able to talk to someone about my health like that. Nobody seems to bother about your health so much when you come to somewhere like this, they all seem to think you're old and that's how it is*." Care home case manager patient

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Patients of the district nurses and community matrons would often allude to their feelings of isolation and vulnerability and uncertainties about how they would cope in the future as their symptoms or situation became worse. Patients often expressed anxiety about the significance of different symptoms and how they and their carers could maintain living at home. Over the nine months several patients talked about their experience of progressive isolation as partners and friends died and children either had significant problems of their own or lived far away. It was important that the case manager understood this; it meant what might otherwise be seen as a trivial anxiety would be taken seriously because the context was and history was known. One woman in an early interview spoke of her fear of being discovered dead in her flat. Another of incipient dementia:

"*It's my worst fear, losing my mind, and I'm so fearful. What will I do and how will I look after myself when I can't think any more? I worry all the time, every time I forget anything, and try my best all the time to make sure I don't*". District nurse patient

These patients repeatedly referred to the importance of being understood and because the nurse case manager knew their story they were their most valued support. Core to this and a source of great reassurance was the regular contact that most of the case managers sustained with patients, through home visits, phone calls, and clinics. Community matrons, for example, were more likely to give the patients their mobile phone numbers. This level of involvement was important to these patients; they talked of feeling protected and cared for. Although many knew they could contact the GP if needed, the nurse was more accessible and there appeared to be fewer barriers to contacting their nurse:

"*I am amazed by what they have done for me and my wife. I feel like I can at least live a bit now, even though I am so ill. I don't worry so much…I don't like to bother the GP all the time he's a busy man*." Community matron patient (final interview at nine months)

The nurse case managers' were a source of support and a means of securing extra resources. Their often in depth knowledge of the meant they gave the patients and carers confidence and informed patients' acceptance of their role as intermediary.

8.4 Intermediary

Many of the patients either had multiple conditions or symptoms that needed regular monitoring and or review. Consequently, they were in contact with a wide range of primary, secondary, and social care services. Patients knew that the case manager was often working on their behalf to initiate these contacts; however, what was valued was the intermediary function the nurse fulfilled. This was when the nurse acted as the patient's representative with other services, absorbed some monitoring aspect of their care (and fed back results to others) and helped to articulate their needs to new services.

This intermediary work meant the patient and often their carer did not have to visit numerous specialists and attend outpatient clinics. The nurse's involvement on their behalf was seen removing both an emotional and physical load for them. One patient summarised it as *"saving a lot of bother"*, another as *"acting as a*

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buffer". There were numerous examples over the nine months of where because the case manager was visiting patients they no longer had to visit a clinic or go to the GP to have their blood pressure monitored. For patients for whom mobility and everyday life were often described as a struggle or a battle, this was a significant and tangible outcome from having a case manager.

Communication with hospital physicians and GPs could be problematic for patients. In two sites there were examples of community matrons and clinical nurse specialists (but not district nurses) either accompanying patients to hospital visits, or supporting patients in their decision to refuse treatments and in one case to move GP practices. From the longitudinal data it was possible to document how the relationships the nurses had with patients developed to allow this to occur. At the beginning of data collection, for example, one patient had expressed doubt about why she had a clinical nurse specialist; however, on two occasions during the nine months the CNS accompanied her to see her consultant. The patient described how the nurse had asked questions that, "*I don't really know how to ask*" and had helped her to express her fears about the need for surgery.

There were, however, notable differences between the models that reflected both the level of need and dependency of the patients and the way that the nursing care was organised. Both community matrons and clinical nurse specialists fulfilled an ongoing intermediary (and expert) role between the patient and the GP and their hospital specialists. Patients characterised these nurses as the "*go between*" and as having the "*authority*" to discuss their care, suggest changes in their treatment and explain their concerns. For these case managers the ability to act as an intermediary was closely linked to their specialist clinical expertise.

Where the patients' problems were ongoing, participants often expressed the belief either that the GP was not interested or that they did not like to 'bother' the GP with what they thought must seem trivial complaints. The nurse would act as an intermediary and ask the GP to visit. In these instances the nurse's contribution was to represent and affirm their concerns and the appropriateness of a GP becoming involved in their care. District nurses, perhaps because of their closer working relationships with GPs, appeared more likely to fulfil this role for their patients.

8.5 Negative consequences of having a case manager

If patients were unclear why they had a case manager or their presenting problems were more diffuse and not linked to a specific need, such as wound care or medication review, some of the negative consequences of case management were more apparent. These patients, although universally appreciative of what the nurses were seeking to do on their behalf, also expressed some concerns.

Regular visits and contact were interpreted as maintaining surveillance of their home situation, building evidence as to whether they were able to remain independent. One woman expressed this recurring anxiety in the monthly interviews; she worried that her community matron would say she could no longer cope and would need to leave her home. Others actively refused services

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on offer and did not want to be identified as someone who needed social support to stay at home. Patients were as likely to refuse as accept services. For them, case management as a process was intrusive and to be tolerated rather than welcomed. Even when the case manager's interventions were appreciated, the increase in visitors and practitioners was not always easy for the older person to deal with:

"*She has been very helpful and since she first came to see me all kinds of people have come to visit. The main problem is that sometimes we don't know who they are and they turn up unexpectedly and expect you to let them in. I got upset one day and called (the CM) who telephoned the social worker on her mobile phone and asked her to come back another day. It's so unsafe having all these people coming and going and not knowing who they are*." Community matron patient

8.5.1 Confusion and duplication of services

An assumption of case management is that the case manager coordinates other services for the patient and acts as the reference point when other professionals become involved in care. Within all the patient narratives, whilst it was clear that although nurses were able to act as the patient's representative, there was duplication and overlap with other services. This could happen in three ways: 1) when other professionals organised services on the patient's behalf without the involvement of the case manager; 2) when the patient independently sought the input and advice of different professionals; and 3) when nursing care was provided by a range of nurses.

Only one of the nurse case managers was part of a discrete multidisciplinary team that had a shared focus (COPD) the others were either working independently, in loosely aggregated groups of professionals or as a member of a skill mixed nursing team. This affected how the nurses fulfilled their role as co-ordinator and point of contact for other services and how they were recognised as case managers within the organisation. When GP hospital and social care services were unaware that a patient had a case manager or had no links to them, this could result in services and referrals being organised without the involvement of the nurse. There were also examples of community matrons not knowing when a patient was admitted to hospital and one when a district nurse's patient was referred for surgery without her knowledge. One community matron patient following a hospital admission received a higher level of disability allowance, and was offered daily home care because of a social worker's intervention.

Patients drew on a variety of sources for help. This usually depended on the type of need, its urgency and to some extent on the availability of the case manager. There was a tendency to see the case manager as a provider and co-coordinator of nursing based health care and social support, but to see the GP and/or hospital as the expert and first point of contact for urgent or new medical needs. The pattern varied according to case management model, for instance, community matrons were more likely to be a first point of contact than the nurse specialists.

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Some patients would choose to consult with both their nurse case manager and their GP over medication and symptoms. Where the nurse did not have a working relationship with the patient's GP there was evidence of tests and treatment review being initiated by both the nurse and GP or the linked practice nurse and, on occasions, disagreements over prescribing practice. This could place the patient in the uncomfortable position of being in the middle.

Although the case managers were clear they would refer patients to other nursing services for technical tasks or ongoing care such as palliative care, patients had difficulty understanding why they were seeing two different groups of nurses They would be seeing the case manager for assessment, review and coordination of care and then other nurses for wound care, insulin injections and monitoring of vital signs:

"*There's one lot that comes every week (district nurses) and they do various tests, like taking my blood and checking my lungs. The community matron seems to be different, though, I don't know if they all work together or not. Sometimes they seem to other times they don't, I can't figure it out she's (community matron) arranged this chair for me and those rails. I think she's the one who got the lady to come from social services as well*." Community matron patient

For other patients there were episodes of care where two nurse case managers became involved. This detailed account by one patient of the care his wife received over several days illustrates how the organisation of work and communication between the patient, the GP, and the community nurse specialist could become complicated:

"*She was ill over the weekend so the community matron saw her and did a physical examination. Her blood pressure was low so she (community matron) asked the cardiac nurse specialist to see her and in the meantime asked the GP to review her medications. She arranged to do a joint visit with the cardiac nurse specialist. …. She (community matron) took blood and completed a screen, the GP gets the test results and will normally feedback to her (the patient) if there is a problem but she did not get the results for some reason. However, the CNS phoned her to tell her that her thyroxin was too high, that her diuretics needed to be reduced and she was also anaemic. Consequently her thyroxin was reduced, diuretics were stopped, and she was prescribed iron for anaemia. She (community matron) reviewed her on Monday and she was feeling fine; she will review her in two weeks time. The CNS will visit again to do an ECG. The patient will also see her GP*." Community matron patient

This patient added that it was very nice to have two nurses involved in her care but it was not clear who was coordinating her care, or how the test results and monitoring of her progress were being communicated between those involved.

8.5.2 Breaks in service provision and decreasing contact

For the patients of clinical nurse specialists and community matrons and, to a lesser extent, the district nurse managers who were part of a larger nursing team, there was an intrinsic paradox. The contact these patients had with the nurses was regular and often time intensive, so, when the nurse was away, on

annual leave or receiving extra training either the patients received no nursing input or a dramatically reduced service. Across all three sites patients highlighted the drawbacks of a service that did not offer continuity. One patient decided to stop using a telemonitoring system when his community matron was on holiday as it became apparent no one was monitoring the information when she was away. Cover for absence at the weekend was always problematic. This district nurse's patient lived alone, and had multiple problems:

"*Usually the nurse is great in helping with what I need and they come regularly. It's been very useful to have the district nurse coordinating other services for me but sometimes it doesn't work very well. When I have a bad time it usually comes on very quickly and sometimes the district nurses aren't there for that. For example, one weekend I couldn't breathe, I tried to find the nurses and they didn't answer*." District nurse patient

It was difficult to know from the patient data if, over time, patients' regular contact and reliance on the nurse's advice and support had unintended consequences of creating dependency. A patient of a clinical nurse specialist described how her confidence in being able to manage her health was shaken when, because the nurse was on holiday, she could not discuss a new medication that she thought had given unexpected side effects. Although the nurses spoke of reviewing patients' needs and decreasing the frequency of contact with the patients as they became more stable, the patient interviews did not suggest that this process was always understood by patients or carers. Seeing less of the nurse case manager was often a source of regret:

"*I enjoy her (community matron) visits and it's a shame she doesn't come and see me so often now, but I suppose she is a busy lady and there are other people who need it more than me*." Community matron patient

It was because the patients valued the regular contact and support they received from their case manager and that even when other services were in place they missed this kind of input. One patient with COPD had progressively deteriorated over the nine months and had several unplanned hospital admissions because of her breathlessness. Her community matron had organised social care, modifications to the home, contact with a community centre, respite care, and, as her condition worsened, continuing care with palliative care support. In the final interview this woman talked of her appreciation for all that the community matron had done for her, but also her disappointment that she hadn't visited for a month and that she did not now feel she could rely on her. For her, the most important thing that the community matron does:

"*is to be there for me, which helps a lot, I can have a discussion and feel safe with her*." Community matron patient

8.6 Comparing case management as one of many services received

The majority of the patients were knowledgeable long-term users of health and social care services. For these patients there was often a tangible difference between the quality of the case management input and their previous

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experiences of what might loosely be termed usual care. Their observations on how the case management services were different and preferable (or not) to other services offered another way of understanding how patients defined outcomes.

The patients of community matrons and clinical nurse specialists often compared the care they received to what GP, district nurse and social care did on their behalf and gave examples how they could ask their nurse case manager anything, initiate contact and have confidence in their expertise:

"*They are excellent far better than a GP or a district nurse because this is their (leg ulcer care) main thing and they know all about it*." Clinical nurse specialist patient

The patients of the district nurses and community matrons in site one appeared to believe that the nurses were compensating for their GPs' perceived reluctance to visit them at home:

"*It's not possible to get hold of the doctor, if it wasn't for them (district nurses) I don't know where I'd be the doctor doesn't even come round here*." District nurse patient

Where there was a separation of the case manager role from the performance of technical care needs (e.g. dressings, spirometry, insulin injections) undertaken by other nursing services, patients would also compare services and what they were achieving. Patients talked of waiting to see the nurse who was their case manager and not raising health concerns with other (community) nurses who they might be seeing every day for dressings or monitoring of vital signs. How much time the nurse gave the patient (as opposed to the frequency of contact) had a direct impact on the patient experience and relationship with the nurse. In this example below the patient's community matron had time to provide support and ongoing education and to help him secure benefits. This input was contrasted with the district nursing service that was visiting daily to take blood and monitor respiratory function and the social worker who had made an assessment visit:

"*You get to feel like an animal or something, you know, knock, knock, come in, blow into this, needle into here, thank you very much and bam they're gone. Even that social services woman could hardly wait to leave*." Community matron patient

In situations where the case manager had delegated particular nursing tasks to community nurses, patients differentiated between the quality of care and saw that the care was organised to suit the nurses' schedule rather than their needs:

"*District nurses are a bit of a pain sometimes they seem to be a law unto themselves when it comes to anything to do with time*." Community matron patient

A recurrent theme about how nurse case managers were different to the usual services they received related to issues of respect and dignity. There were examples given of staff in hospitals and social care services being patronising and abrupt in their care. In contrast the relationship with the case manager was more predictable and equal. Patients knew when they would visit, were confident

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they could initiate contact and could give examples of shared decision making even when this involved refusing services offered. This was most evident in the narratives of the community matron patients:

"*I may be a bit old and a bit doddery but that doesn't give anyone the right to think they can come and go as they please and take charge of me. Who do they think I am, there's just no respect amongst these people…the nurses are nice though very respectful even if I told (the community matron) off for sending round those other people*." Community matron patient

Not all the case managers' care was represented as better than other services. There was one example when following an initial assessment and treatment of a virus with an antibiotic (sic) a case manager had referred a woman with osteoarthritis, hypertension, and recent sight loss, to the district nursing services for monitoring of her blood pressure. Their visits had been erratic and there had been no follow up from the nurse practitioner case manager over the nine months of the study. This had increased the patient's feelings of abandonment. The patient compared this experience to a previous one of being case managed where a social worker had maintained regular contact, had arranged for her to receive equipment and have modifications to her bathroom. Whilst the nurses were "*all extremely nice people*" she thought that the care provided by the nurse case manager was inadequate.

8.7 Differences between the case management models

From the patient perspective differences in case management approach were discernible and their observations reflected the priorities and foci of the nurses (see also chapter 5)

Patients of the community matrons emphasised how much time the nurses gave them, their willingness to listen and the services they secured and that they were able to do more for them on their behalf. The community matrons were identified as very significant people in the lives of their patients. The patients of the clinical nurse specialists and the district nurse case managers also appreciated regular contact and continuity but were more likely to emphasise the technical and enabling work that the nurses achieved on their behalf, helping them to manage their disease or symptoms.

It is difficult to comment on the patient experience of the nurse practitioner and the care home support team, because there were fewer patients and considerably less contact when compared to the other models. Older people in the care home could identify that the nurse case manager had organised extra services for them (e.g. physiotherapy) and were appreciative, but they did not appear to recognise that their care was being reviewed or monitored by her. One of the nurse practitioner's patients was clear that the nurse practitioner was not working as a case manager and was not following up referrals or monitoring the patient's health.

There was overlap in how the patients and carers of the three main groups of nurse case managers (district nurses, community matrons and clinical nurse specialists) described the valued of the case manager role. These attributes

(expert, support and resource and intermediary) were described as key characteristics of the nurses working as case managers regardless of model.

8.8 Discussion

The patient narratives and experience of health over the nine months of data collection forcefully demonstrated how, as well as the major exacerbations of their disease (and were demonstrated in the findings of chapter 6). In addition to this patients were dealing with bereavement, loss of function and independence and anxieties about their ability to cope in the future. They were appreciative of the physical and disease management benefits of case management but, as important, were psychological support and regular contact. The nurses' involvement made their life easier and the feeling of confidence that having a nurse case manager brought was seen as enabling. From a patient perspective the quality of the relationship (as opposed to the quantity of contact and specific tasks achieved on their behalf) was the defining feature of good case management. This relationship was robust when the patient had confidence in the nurse's expertise, was supported in times of crisis and the nurses' interventions mirrored their concerns and priorities.

There are many representations of old age and living with chronic disease that range from this being an experience of inevitable decline and deficit to one that promotes a very positive experience of patient empowerment and healthy ageing as avoiding or escaping this. Neither of these theories fits with the experience of community dwelling older people or their narratives of how they engage with the challenges of fluctuating health, social isolation and increased vulnerability to adverse circumstances (Reed et al 2003, De Lepeliere et al 2009). A nurse case manager, who listened, was responsive and who worked on the patient and their carer's behalf, defined quality care.. Community matrons appeared to be able to give the most time and resources to achieve these relationships, however, patients of nurses working to more loosely configured models of case management identified similar indicators of effectiveness. When the nurse case management was disaggregated into oversight with nursing tasks delegated to others, the patients were more negative about the quality of their care.

The importance of continuity and relationship in primary care has been extensively discussed often in the context of the relationship between the GP and the patient (Freeman et al 2003, Haggerty et al 2003) Case management models offer continuity, from a provider perspective this relates to efficiency and effectiveness of service provision. From the patients' perspective however this was expressed in terms of the relationship and support they received from the nurse over time being a notion of continuity that is based on patient centeredness (Guilliford et al 2006). More recently, research on how patients with long term conditions understand continuity, has suggested that patients value longitudinal continuity and relational continuity because they facilitate the establishment of a "shared personal and clinical history between two individuals" (Cowie et al 2009:83). This is what the patients identified as an important component and benefit of having a nurse case manager.

These findings echo those of Sargent et al (2007) who interviewed patients newly admitted to a very structured and high profile nurse case management

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model (Evercare) or the caseloads of recently introduced community matrons. They identified five categories of support that the patients identified: clinical care, care co-ordination, education, advocacy and psychosocial support. All of these are components of the three areas of care; clinical expert, source of support and resource and intermediary identified in our study. In Sargent et al’s (2007) research, the nurse case manager was seen as a unique source of education and advice, helping patients to manage their condition more effectively. Whilst advice and education were recognised as important nursing contributions there was less evidence from the patients in our study that they had achieved greater independence or self-efficacy because of nurses’ educational input. The patients in our study reported smaller, more incremental, changes in how they lived with and managed their long-term conditions. The educational benefits had helped them to manage their anxiety and to use strategies to ameliorate symptoms or recognise when these were becoming worse. These benefits were inextricably linked to the level of support and confidence patients had in the nurse’s expertise.

Sheaff et al (2009), drawing on the findings from the same Evercase study, observed that case management supported patients' independence by enabling them to continue to live in their own homes but simultaneously increased the patient and carers’ practical and psychological dependence on their case manager. These findings reflect our own when comparing a wider (and more loosely defined) range of case management approaches. For this study it raises the question as to whether what was being documented was case management or something else. For the majority of patients, nurses were compensating for the perceived shortcomings of other practitioners, most notably GPs, and creating links between individual services that did not cater for the range and complexity of patients’ needs. Even with regular nursing involvement data collection over the nine months showed these patients would continue to experience exacerbations, falls, infections, and changes in their systems of support (see chapter 6). Nursing involvement was crucial addressing the uncertainty of the patient’s situation. One that was not going to improve but could be stabilised, ameliorated, or ultimately palliated. This challenges the assumption that patients with multiple needs, once specific issues have been addressed, can be referred on for technical review or less specialist input.

8.9 Conclusion

There were more similarities than differences in how the patients and their carers described the impact and value of the different nurse case management models. It was striking that patients and carers were able to draw on their experience of health and social care to compare services and articulate how nurse case management was preferable to other nursing or primary health care services. This comparative analysis meant they knew (but not necessarily how) that the nurse case managers were improving their access to and use of services and the overall quality and continuity of care were preferable to what they had previously received. The narratives suggested that the nursing contribution across the models was mainly substitution and supplementary, filling in the gaps and deficits of existing provision. The nurse case manager was identified as providing care that was complementary to other services when she was drawing on

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expertise others did not have (e.g. clinical nurse specialist working in tissue viability) and in providing ongoing care and contact and continuity in the absence of specific symptoms or events. However, for the patients having a nurse case manager (as would be true for a GP) was not ongoing and it was a source of regret when their care was delegated to others or contact reduced. As chapter 5 demonstrated, sustained involvement of a case manager, who retained case management functions, over nine months was not the experience of the majority of patients, regardless of which type of nurse case manager.

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9 The carers' experience of nurse case management

9.1 Unpaid Carers

This chapter considers the experience of nurse case management from the perspective of the carers of the patient with long term conditions. The methodology is reported in full in chapter 4.2.1. In the study overall 19 patients had family members they reported were undertaking carer activities for them: that is 40 percent of those living at home. Fifteen were spouses and four were adult children. Fourteen patients reported that they received assistance for activities of daily living (ADLs) from a paid source (typically a home care worker): that is 29 percent of those living at home. Two people reported they received assistance both from a family member and from a home care worker. Care workers were the employees of local authority social services departments, or of third sector agencies, such as Age Concern, or were organised and paid for by the older person or their family (see Chapter 8.2). Table 72 describes the source of support as received by patients of the different types of nurse case manager.

Table 72. Source of assistance with activities of daily living

Type of Support	Patients' type of nurse case manager			
	CM (n=21)	DN(n=11)	CNS(n=13)	NP(n=3)
None	2 (10%)	2(18%)	9 (70%)	1 (33%)
Unpaid or family carer	9(42%)	5(45%)	2 (15%)	1 (33%)
Home Care Worker or other paid assistance with ADLs	10(48%)	2(18%)	2 (15%)	1(33%)
Both informal carer and care worker		2(18%)	0	0

9.2 Findings

All carers providing assistance with ADLs (n=19) were invited to take part in the study and 11 (58%) consented to be interviewed. Reasons for refusal were various. One person declined because he was not interested, three declined because they did not have time. Five declined because they did not identify themselves as having a carer identity.

Eleven carers were interviewed at time point 1 and then asked to participate in a second interview at the point when their family member was about to end contact with the study. Eight carers were interviewed a second time. One of the carers had died and two others declined (See table 73).

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Table 73. Nurse Care Managers experienced by participating carers.

Type of nurse case manager and nursing service experienced	Number of Carers at Interview 1	Number of Carers at Interview 2
Community matron only	4	3
Community matron and district nursing service	2	2; 1 had only the CM at time point 1 (plus one declined interview)
District nurse(s)	4	3 (NB one carer had died)
Specialist nurse	1	Declined interview
Total	11	8 interviewed

Of the 11 carers interviewed at time 1, ten were female and one male. Ten were spouses and one was a daughter, who stayed part of the week with her father. Seven were aged 60-69, three were aged 70-79, and one was aged just over 80 years. Four carers reported no health problems of their own. The remaining seven reported multiple long term conditions themselves e.g. diabetes, asthma, cardio-vascular disease, and arthritis.

Four carers at time point 1 had experience of only community matrons, the same number were in contact with district nurses and two carers had experience of both; a number that increased by time point 2 to three carers although one of these carers declined a second interview. The Caring Activities

Carers undertook a broad range of activities to assist their relatives. For example, one carer, whose relative was being 'case managed' by a clinical nurse specialist, reported the least amount of activities to aid her mother in activities of daily living (ADL) and a corresponding low Carers Strain Index (CSI) score of 0 (Table 68):

"*I don't do that much, we just get on as best we can... I make a cup of tea for her and I drive her places when she needs me to, but that is what I used to do*." Carer interview 1

At the other end of the spectrum there were carers who assisted in most of their spouses' activities as in this example:

"*I do everything for him when the [home care workers) aren't here; my whole life is driven by his needs. …..I would say I spend at least 20 hours a day caring for him. My only respite is when the home carers are here for meals and I can go and have a bath, or rest for a while, but I never really switch off and I hardly ever go out, unless my daughter comes to visit us here*." Carer interview 1.

This carer reported the highest CSI score at both interviews. Carers of people in receipt of district nursing services tended to report higher CSI scores than those

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receiving community matron services but as can be seen from Table 57 this was not consistent and the numbers so small that no firm conclusions can be made.

Table 74. Carer reported CSI Scores

	CSI Score (a score of 7 or above indicates carer strain)	
Carer receiving type of nurse case manager	Time point 1	Time point 2
Carer 1 CM only	2	2
Carer 2 CM only	7	4
Carer 3 CM then CM & DN	5	5
Carer 4 CM & DN	10	Died
Carer5 CM only	7	11
Carer 6 CM & DN	4	4
Carer 7 DN only	7	7
Carer 8 DN only	2	declined
Carer 9 DN only	12	12
Carer 10 DN only	10	12
Carer 11 CNS	0	declined

Those carers interviewed at two time points all reported that the condition of the patient in the study had deteriorated and that they were providing more care than they had done at the time of the first interview, as in this example:

"*He is much less mobile and much more dependent now. I really worry about him these days, I think he is going downhill, you know, in his mind. I always dress him and have to help in and out of his chair and in and out of bed now*." Carer interview time 2.

The carers' views of their relatives becoming more disabled and more dependent on them over the course of the study echoes the findings from the patient level data reported in Chapter 8.

9.2.1 The Nurses' activities

Community matrons

The carers described the community matrons as undertaking physical assessments of their family member each time they visited as well providing 'practical' advice and information about the conditions(s). One carer described the CM as spending up to an hour with the patient each week. In that time she

undertook physical assessments, talked with the patient about how they felt, spent time teaching the person about their condition and strategies to improve and cope with some of the symptoms, particularly if they seemed to be getting worse. One carer reported that this had the effect of making the patient '*more confident and up beat'* (carer interview 1). Only one CM was reported to provide any 'hands on' treatment or care of the patient.

The carers of patients receiving CMs' services reported that CMs not only referred the patient and themselves to other services e.g. occupational therapist, social worker, physiotherapist but followed up those referrals as well as checking what other services were going to provide or advise for the patient. The carers described the CMs 'sorting out' the other services when there were problems or delays. The carers all reported a great deal of satisfaction that there was this level of follow up and relief in some instances that someone else was doing that work for them.

Two carers supported by a CM reported that since receiving her service there had been a reduction in or no hospital admissions for their relatives. One stated that in the past when the patient had exacerbations they would have called the ambulance to go to the Emergency Department; now they acted on the CM's advice on what to do in an exacerbation and then, if still concerned, rang her to discuss what to do next or moved to the next agreed step in the exacerbation plan.

The carers described the CM as being there for 'both of us' (Carer 5 interview 1). They reported that one of the main activities of the CM was providing them with emotional support in their caring activities, as illustrated in this quote:

"*She has given me huge reassurance; she is always there when I am worried or even if I only need to talk, to witter on about him or about me. She is a mine of information; she shows us practical ways to cope and most of all she helps us both feel even if it is difficult it's not completely hopeless*." Carer interview 2

All of the carers with CMs reported that they knew if they called the CM on her mobile telephone, she would respond and two of them knew she would be with them within the hour if necessary. All acknowledged the benefit they received from knowing there was someone they could talk to and who would listen to their concerns. The carers described the CM as someone they could share their worries with, summed up by one carer as a "*godsend*" (Carer interview 1). Some of the carers contrasted this type of activity by the CM with the absence of it from their general practices and from the district nursing team.

In the first interviews, the carers all reported that they with the patient were making decisions about using and contacting health and social care services and arranging appointments but that this was not always effective. By the second interview two carers reported that the CM was setting up appointments with the GP and arranging other services as in this example:

"*She [the CM] has made a great deal of difference because she seems to be in control of everything which is a comfort to me. Like when I got confused about social services coming. She sorted that out for me*." Carer interview 2

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District Nurses

Carers whose relative received the district nurses' (DN) service described the DN activities as mainly a type of hands on treatment or care e.g. wound dressing or administration of insulin:

"'*At the moment they come daily and sort out his dressings, clean up his legs, check all is well. They give help and advice when we need it*." Carer interview 1

Their responses reflected that their care came from a team of nurses and that most of the nurses came to do a task and then left:

"*The district nurse is a nice lady and always there if we need her although we don't see her very often, mainly the other nurses*." Carer interviews 1

"*I sometimes talk to the [district]nurses who come every day but usually it's a quick visit from them, they do whatever they need to do and then they leave*." Carer interview1

The carers all reported that they knew they could get support from the district nurses if they asked but either they didn't feel their problems were severe enough to ask or they felt that they should be able to manage and not bother the district nurse:

"*I know I could call on the nursing team for just about anything and they will know what to do but I try not to do this unless it's really serious*." Carer interview 1

Two carers reported that the district nurses had helped them obtain a day centre place and referred them to a social worker. One carer reported that the district nurse had helped her change their GP from one with whom they had a poor relationship to one who was now calling once a week to check up on the condition of the patient.

The carers all reported that they, with the patient, decided when they need to consult other services such as the GP or hospital and made all the arrangements. There were no reports at any point that the district nurse had taken a more prominent place in these activities as the some of the CMs were reported as doing.

9.2.2 Comparing and contrasting the carers and their views of the district nurses (DN) and community matrons (CM)

The carers receiving CM support reported the CMs undertaking assessment, planning, review and follow up activities that seemed to be akin to the case management cycle. In general, carers did not report the district nurses (DN) providing this sort of activity. The carers reported all the CMs as active in making referrals, introducing them to services, and communicating with other services of their behalf. Only two of the carers reported the DNs making referrals to other services. The DN and their team were reported to predominantly provide hands on technical care e.g. wound dressings. Carers noted how little time the DNs spent with the patient and that different nurses provided the care. In contrast,

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the CM was the single contact and offered time for the carer as well as the patient.

While the carers receiving CM and DN reported that both offered emotional support and information to the patient and the carer: the description of the amount of support by CMs to carers and their response to that was qualitatively greater to that described as offered by the DN services.

The carers reported the CMs spending time teaching the patient and the carer in detail about how best to manage their LTC and remain as independent as possible. None of the carers described the DN team doing this type of teaching and information giving; apart from teaching one carer how to administer daily insulin injections instead of the district nurses.

9.2.3 How carers perceive CM and DN activities by types of role in the organisation and delivery of health care

From the carers' accounts it is possible to see that the CMs are providing services that substitute for and/or supplement the GP and possibly social services' care management activities in caring for the patient and putting them in contact with appropriate services. The accounts also suggest that the CMs and sometimes the DNs supplement the activities of the carers themselves when needs are increasing. The striking feature from the carer perspective is that the CM paid attention to their needs as a carer of someone with a LTC in ways they did not discern from DNs or GPs, or social workers care managers (although these were not discussed in great detail).

9.3 Discussion and Conclusions

This chapter has described both the involvement of carers in nurse case management models and the carer's experience of nurse case management. The carers perceived the community matrons as providing very different type of support from other types of primary care service. It was not clear as to whether the community matrons were providing a complementary function in the service system or just supplementing for other services that did not have the resources, skills or mandate to provide adequate support. Such debates are long-standing in relation to carers' support (see Twigg and Atkin 1994). They point to models of carer support that see carers as co-producers of care (with professional roles in their training and skill development), to providing carers with counselling in terms of their relationship and needs (such as emotional support), to engaging with carers to supplement their care (by drawing in other expertise or equipment or services), thus sustaining this type of support, to substituting for carer support, perhaps in the realisation that the situation is increasingly untenable.

Future developments in the area of case management may need to relate more to the carer context so that these issues can be built into commissioning models and evaluations. Our study suggests that the dyad relationship between case manager and patient needs more often to be seen in the light of a three party relationship or triad of case manager, patient, and carer. Finally, this study did not explore the activities and relationships between care workers and case managers. Their contacts and interchanges, if any, were perhaps mediated by

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patients and carers. In the light of moves to personalise social care services (DH 2007c), this axis could be usefully interrogated to see if there are agreements about outcomes and what are the most effective means of communication and exchange.

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10 Local stakeholders perceptions of nurse case management

A stakeholder analysis methodology was employed to address elements of the following research objectives (section 1.5):

- Identify the drivers that have stimulated the development of models of chronic disease management that involve nurses as case managers
- Describe the range and type of nurse case management models and the ways that they involve service users and carers
- Evaluate the impact of nurses' contribution to the experiences of patients and carers
- Identify the factors that enable nurse case managers to contribute most effectively to successful outcomes of care
- Evaluate the impact of the nurse case manager's contribution upon the cost, quality, effectiveness, and organisation of the care provided
- Identify the factors that sustain the models of nurse case management over time.

10.1 Stakeholder analysis

A stakeholder analysis (Brugha and Varvasovszky 2000) was undertaken in each case study site to inform the broader understanding of the context and setting for nurses acting as case managers for people with long term conditions. The purpose of a stakeholder analysis is to identify the viewpoints from different perspectives, identifying where there is agreement or disagreement (Brugha and Varvasovszky 2000). Ethical review and permissions were obtained as part of the case study phase (see Chapter 4).

10.2 The method

The aim was to obtain up to ten interviews in each site with at least half from service users. It was anticipated that professional and organisational viewpoints would be obtained from a variety of informants including: general practitioners, hospital consultants, community service managers, Local Authority Adult Services (social services) managers, voluntary organisations and health and social care service commissioners. Informants were invited to participate in a brief semi-structured interview, either face to face or by telephone, to discuss their perceptions of nurses as case managers in that area, how the nurses' contributions fitted with other services and how these were judged within local models of care delivery, and how nurse case managers were received by other services and service users. The interviews took place over the period of the case study phase in each site. The interviews were recorded with permission, transcribed and then the tapes deleted. The transcripts were analysed by three researchers independently, using a framework methodology (Ritchie and Spencer

1994) and using NiVO software. Differences in analysis were discussed against the data until agreement was reached.

10.2.1 The Informants

Thirty interviews were undertaken (see Table 75). Recruitment of service user representatives for this element of the study proved difficulty. Despite repeated contacts and requests with local branches of organisations such as Age Concern, and through local Exert Patient Programmes, the study was only able obtain interviews on this topic from four service user representatives. Discussions within the research team and with the service user reference group suggested possible explanations, e.g. the term 'nurse case management' was not one familiar to these groups, time pressure on volunteers and staff in voluntary organisations leads them to prioritise where they invest their energy and this topic may not have been seen as a priority.

Table 75. Roles of informants interviewed

Type of Informant	Number of Interviews
Service user representatives	4
General Practitioners	12
Hospital Consultants	2
PCT Provider Services Managers	5
Local Authority Adult Services Managers	2
Commissioners : Joint Health and Social Care (PCT and LA)= 1 Health Care only (PCT)= 1 Leading practice based commissioning consortia =3	5
Total	30

10.3 Stakeholder perceptions

There were marked similarities between the different stakeholder perceptions in the three sites. This will be reported by stakeholder type before commenting on issues specific to each case study site.

10.3.1 Perceptions of service user representatives

Four interviews were undertaken covering the 3 sites. The common elements across these interviews were, first of all, limited recognition or comprehension of the term 'case management by nurses':

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"*Case management by nurses. I don't know about it really….I don't think it's something we have ever discussed here… Oh yes, I've heard about those community matrons. I had forgotten about them. I think you have to be really bad to get one of them, don't you? Nice idea, having someone who can come and look after everything for you. How do they get their patients? How do you get a community matron?…. The title sounds a bit grandiose. Are they going to come in and tell you off for not having your house clean enough*?" Informant

As service user informants talked they all considered that a nurse case manager could be very helpful to some individuals:

"*The concept is marvellous. I'm not clear how extensive this case management is though? How much can they do for people? I know one of our members has a nurse who seems to look after social services and all kinds of things like that That surprised me, the social services thing, I didn't know nurses could do that, but it makes sense*." Informant

As the service users talked about the concept they all started to identify the type of people who would benefit. As they did this they also started questioning the role, for example, in relation to people who prefer to remain independent:

"*What about if you are, you know, one of those independent sorts. I'm thinking of my neighbour here. She's a nice sort but she wobbles and wheezes her way around and won't accept anything you want to do to help her. I wonder what someone like that would think of a nurse who wanted to come in and sort everything out just because they could*?" Informant

They also questioned the role in relation to other health professionals such as district nurses and GPs:

"*I can't really work out why the district nurses can't do some of that stuff [that a community matron does]… The idea is good: one nurse who looks after it all for you, except I think the GP should be doing more of than in the first place*." Informant

Two of the informants offered the view that, in their experience, the district nurses only visited people to undertake technical tasks .e.g. take bloods for investigations or give injections in as short a time as possible, rather that take a broader interest in the health problems of the patient and their family.

10.3.2 The General Practitioner (GP) perspectives

Twelve GPs were interviewed in all 3 sites. All worked with district nurses, practice nurses, specialist nurses, e.g. in palliative care teams, and were either working with community matrons or had met one designated for their practice /area. The GPs also saw their role as a clinical case manager, who worked with others to address patients' needs:

"*As a GP I am involved in all aspects of managing chronic conditions with patients. I suppose that from their point of view my role is mainly diagnosis, medication and initial information and then being here for their ongoing care, but I see it as the complete package. I will follow through wherever a patient needs*

it, and if a patient has a chronic illness I see my role as being to provide medical care and referral for all their health needs. I also refer on or write letters to social services and housing and so on, if a patient says they need it."Informant

The GPs offered different views of the district nursing service. On the one hand, those with closely linked, long-time district nurse(s), who also used shared patient records with the practice, were viewed positively in their close working with the GP and this was said to be to the patients' benefit:

"*I have an excellent district nurse linked to this practice. I think she does what you might call case management as well. She identifies some of my patients who have complex needs and talks to me about what extra care they might need, and goes out to those patients more than she would normally. She also inputs into the practice medical notes when she sees things she thinks I should know or if she does any patient care*." Informant

On the other hand, those experiencing loosely linked district nursing teams with high staff turnover and little communication with the GP or the practice, except in writing, reported an ineffective district nursing service of poor quality, which their patients also commented upon:

"Patients with multiple problems require telephone to telephone or face to face contact…a 5 minute chat is better than a fax which is what we get now from the district nurses." Informant

"*Typically our patients are not impressed [with the district nursing service] they never see the same person twice and, for patients with a chronic problem, it can be quite confusing."* Informant

Overall the GPs with a less positive experience of working with district nurses saw them as focused on technical tasks e.g. wound dressings, administering injections, rather than a broader patient focus:

"*The district nurses are task driven not case driven*." Informant

All GPs were sceptical as to the extent community matrons could reduce hospital admissions or impact on GP workloads with the very complex, often 'chaotic', patients with multiple long term conditions. Some of the GPs interviewed had very limited experiences of working with community matrons. However, those that worked more closely or over a longer period mainly reported very positive experiences:

*"I was pretty sceptical in the very early days about community matrons, I have to say. They seemed to be thrust upon us with very little planning, and having a new service of that nature suddenly having to fit in with our existing patterns of working was quite a challenge. However, they have worked very well, and I value what they do highly. They cater for that proportion of our patients who need more than we as a surgery can realistically provide in such depth, and have become an integral part of what we do."*Informant

A recurrent theme was the question of where the community matron role *fitted* with the existing GP services and where the boundaries of the work started and ended in relation to another health professional's role. These issues caused not only tensions between professionals but also confusion for patients:

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"*I know I have some patients who are in the community matron's caseload and they sometimes get confused about whether to contact her or to call the surgery to see me*." Informant

"*She's very good [the community matron] but sometimes she ends up doing things I think could be done here in the practice, or I get complaints from the district nurse that the community matron is doing something the district nurse should be doing*." Informant

All but one of the GPs questioned the 'stand alone' community matron post and offered an alternative view of team settings where nurses with advanced level skills should be located. The GP who did not offer this view had a community matron based in and working solely with his practice's patients. The other GPs suggested that: more nurse practitioners should be trained to work within practice teams, that community matron type nurses should be part of community rehabilitation teams and of rapid response /intermediate care teams.

Many of the GPs considered the current model of community matron as resource intensive and questioned whether the resources financing it might be used to greater effect in other ways. Only one GP could identify a reduction in demand on the GP from some, but not all, patients with multiple conditions receiving community matron services.

10.3.3 The Hospital Consultant perspectives

Only two hospital consultants agreed to be interviewed, despite a number of approaches to a range of consultants. They were in two different sites. There were strong similarities in their viewpoints and also similarities with the opinions of the GPs. They, like the GPs, were sceptical about the extent to which the community matron role could reduce unplanned hospital admissions of people with very complex co-morbidities and social circumstances. One had since seen a positive contribution by one community matron who accompanied a patient to outpatient consultations. The other reported the positive contribution of specialist nurses in providing education, information, support, and direct access for patients, as well as primary care staff such as practice nurses, in ways that they added to the contribution of the medical team. One consultant echoed the GPs' questioning of where resources were best placed in a financial constrained system, expressing frustration that community matrons appeared an expensive resource when funding was being cut in the local hospital unit, to the extent that equipment was not being bought that would enable the consultant to help people at a much earlier stage of their chronic disease.

10.3.4 The Local Authority Adult Services perspective

Two interviews were undertaken in 2 sites. One was a department manager and the other managed a specific service. The themes in these interviews echoed aspects of both the service user views and also the GPs. Both interviewees had limited contact with community matrons and were uncertain as what the term 'case management by nurses' really meant, particularly in relation to 'care management by social workers'. Both queried when a client's '*case worker* 'should be a social worker and when it should be a nurse. Both informants could

see benefits of nurses as case managers in situations when a person had complex health needs, where social care staff did not have enough medical knowledge or were not viewed by clients as having sufficient knowledge. Both informants argued for good communication between health and social care professionals supporting the same client, irrespective of job titles or roles. They cited multi-disciplinary teams such a community rehabilitation teams and intermediate care teams as good models of supporting people to remain in their own homes.

10.3.5 PCT provider services managers' perspectives

Five interviews were undertaken in 3 sites. All sites provided district nursing, community matron and specialist nurse services. All informants thought there was confusion or at least a lack of clarity in the minds of commissioners and others about the meaning of the term 'case management ', who should be undertaking that type of role and with which population group:

"'I'm not sure if we [the provider organisation] understand the nature of case management; the same for the PCT" Informant All informants reported that government targets had led to the creation of community matron posts in their area to undertake case management activities with older patients at risk of unplanned re-admissions to hospital. Each area had introduced community matrons in a different way (see Chapter 5). All reported a slow introduction of community matron services, not least because the nurses concerned invariably needed further skills development and training to acquire the skill levels of an advanced practitioner with the patient group their organization had decided to focus upon:

"*When they [community matrons] first came into the post they did not have all the skills to manage every long term condition they were working with. At that time there were a large number of hospital admissions related to COPD exacerbations. Hence in order to reduce admissions the CMs were training to increase their respiratory knowledge base; subsequently they have had training on other conditions as well independent nurse prescribing and other thin*gs." Informant

All informants reported that community matron posts were established despite the resistance from, at least, some GPs in their areas:

"*There are some GPs who believe that the introduction of the CMs was at the expense of district nursing and therefore they have a fundamental problem with the concept as they see it robbing another budget…*" Informant

All the informants reported that patients valued the community matrons but noted that the monitoring of community matron activity and the impact were very limited locally. This was particularly so when the posts were first established. All informants discussed the anticipated impact of the community matrons as reducing unplanned hospital admissions. All reported that this had been impossible to identify and isolate in monitoring systems. Others reported reviewing the community matron posts (currently occurring in all three sites at the time of the interviews) through mechanisms including accessing patient

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perspectives, carer perspectives and establishing the percentage of time spent in direct patient contact.

The informants considered that case management activities, as they perceived them, were not undertaken by community matrons exclusively, although one informant thought that community matrons undertook case management in its 'purest form'. They thought that other nurses such as district nurses and specialist nurses used case management techniques with some patients:

"At the present there is internal debate about whether specialist nurses or Community Matrons should be providing case management. I think a mix of the two is most effective but the Trust is not so sure." Informant

One informant reported difficulties in the interface between different teams (and nurses) who 'case managed' when patients needed to access new services. The example given was when a patient, receiving the community matron service, was referred to the palliative care team. It was not clear at this point who was to be the main point of contact for the patient and carer and who was take what role.

One informant reported variations in the way that the different groups of nurses' undertook case management. In her experience, nurse specialists based their case management around short-term aspects of care, such as treatment and education. She reported, as did the other informants, that the district nurses in the main were very limited in any case management role, focusing only on the delivery of nursing care:

"*The district nurses go in with their eyes shut and just deal with the wound rather than going in looking at a patient who needs help with other things beside the wound, and their carer who needs social support , and thinking there are some things I need to do here* ..." Informant

Two of the informants were able to explain that behaviour in terms of the staffing and resources available to the district nurses (DNs):

"*It is an area that could be improved but they are not able to do this since they do not have the capacity. The DNs have enormous caseloads which would need 5 or 6 case managers per team in order to manage it effectively*." Informant

All reported that the district nursing service in their areas had been reorganised in the past twelve months, including in changing some senior posts into community matron posts. The financial situation in all the PCTs over the financial year 2007/2008 meant all had had to contribute to financial savings, such as through freezing district nursing vacancies. All reported that the PCT commissioners were scrutinising the district nursing service, and other community nursing services, and they were either re-organising the service or could see that this would be a likely consequence. Re-organisation invariably meant: a) changing the configuration of the nursing teams to the general practices they linked with; and b) increasing the number of nurses and changing the skill level/grades present in each district nurse team:

"*Currently there are 8 [district nurse] teams, some of which only have 4 nurses in them. We've also had some team leaders leave and have other staff nurse vacancies so the teams will be amalgamated into larger teams in the next 6 months*." Informant

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All these informants reported that their organisation and the wider commissioning community were questioning the value of the CM posts, as currently configured:

"*It is not likely that the CM service will be increased and we are worried that as CMs leave, for whatever reason, they many not be replaced - case management is seen as low priority because it caters for so few people at such high cost*." Informant

Informants in two of the sites considered that community matrons should be leading skill mixed teams of staff to deliver some of their activities, as one way of reducing costs.

In all sites managers and commissioners were looking at mechanisms of integrating community matrons and district nursing services with wider local authority social care services, in the form of multi-disciplinary teams.

10.3.6 Commissioners' perceptions

Five commissioners were interviewed covering the three sites. All considered our questions of nurse case management and commissioning nursing services within the broader system of service delivery. The GPs within the PBC consortia discussed these within the terms of practice patient populations and the activity of GPs. The commissioners from the PCT and Local Authority discussed them only within the sphere of services they personally were responsible for commissioning. The GPs noted that nursing services were not yet being discussed within their consortia as they were focusing on the management of conditions, such as diabetes, between general practice and the acute sector. They questioned the role of community matrons within the broader delivery of services and were more concerned with the variability of district nursing services in quality and relationships with general practice. In this they echoed the GPs' perceptions as reported above.

The two PCT and Local Authority Commissioners reported that they were concerned with effectiveness in addressing the issues of people with long term conditions and were not particularly wedded to the notion that nurses should perform case management. They confirmed that the introduction of community matrons was in response to central targets and that there was still much local debate as to how to use these posts to best effect. They both highlighted the lack of monitoring information that reported on the activity and effectiveness of community matrons, at the same time as noting that "*all community services tended to be information light*". Both questioned whether the focus on people with the most complex needs was correct or whether interventions with people at an earlier stage in their condition would be more effective in the total system. They reported looking at other types of services, such as tele-monitoring, and emphasised the need for health services to deliver more education for self-management. One noted this was a particular strength of specialist nurses but both reported that the Expert Patient Programmes in their areas had received no referrals from nurses.

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10.4 Discussion and conclusions

Despite the differences in the populations, geographies and health service economies of the case study sites, there was commonality of views among each stakeholder group.

The service user representative views, despite few in number, illustrated the lack of public knowledge of the concept of nurses as case managers and the differing views about the value of nurses in such roles. Many other informants echoed this lack of clarity and confusion between professionals over the term 'nurse case manager'.

Managers and commissioners confirmed the evidence from the national survey that the creation of community matron posts was a direct response to the central targets (see chapter 3), rather than a conviction this was a model of service delivery they supported. The managers were best able to describe the contribution of different types of nurse case management and to provide, in the main anecdotal, information of benefit. Some managers and the commissioners questioned the cost-effectiveness of what they saw as the expensive resources of community matrons.

Community matrons had not evolved organically from the collective experience of community nursing or primary care, but were imposed, triggering negative responses from other disciplines about their likely impact. Evidence from the GPs, the managers and the commissioners suggested that there would be little sustaining the current configurations of nurse case management in community matron or district nursing services in the future. GPs, hospital consultants, commissioners, and managers pointed to the investment (resources, training, and so on) in Community Matrons at the expense of investment in other services. Views of alternative ways of using local funds varied but included investment in the district nursing service, nurse practitioners in general practice teams, multidisciplinary teams and specialist equipment. The evidence suggests that the local NHS and social care system in all three case study sites were fragmented with each part only seeing the question of case management from its own perspective, not that of the patient, or of the whole care system.

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11 Discussion, conclusions and recommendations

This study aimed to inform the NIHR SDO Programme about the types and impact of the contribution of the nurses as case managers in different models of chronic disease management. The study was conducted in two phases over three years and incorporated four elements: a literature review, a policy review, a national survey and multiple case studies. Each of the elements had limitations and these have been discussed in sections 2.7, 3.3.11 and 4.3.6 respectively. This chapter draws each of the elements together to consider them in the context of the study objectives and then within the theoretical framing that allows the findings to be generalised and transposed to other settings (Yin 2003).

The specific research study objectives are considered in the following sections:

- Describe and classify the roles of nurse case managers in models of chronic disease management (section 11.1),
- Identify the drivers that have stimulated the development of models of chronic disease management that involve nurses as case managers (section 11.2),
- Describe the range and type of nurse case management models and the ways that they involve service users and carers (section 11.3),
- Evaluate the impact of nurses' contribution to the experiences of patients and carers (section 11.4),
- Identify the factors that enable nurse case managers to contribute most effectively to successful outcomes of care (section 11.5),
- Evaluate the impact of the nurse case manager's contribution upon the cost, quality, effectiveness, and organisation of the care provided (section 11.6),
- Identify the factors that sustain the models of nurse case management over time (section 11.7).

The chapter then turns to considering the study's overarching questions within the theoretical framing. It concludes by suggesting issues that required further investigation and makes recommendations for service providers and commissioners.

11.1 Classifying the roles of nurse case managers

It is a national and international policy priority to improve the experience and care of people with long term conditions and their carers through multi-disciplinary models of chronic disease management (chapter 1). Research on the contribution of nursing to models of chronic disease management, and specifically case management, either assumes that it is self evident what the nursing work is and never detail it, or creates and evaluates nursing roles. The latter are invariably represented as new without reference or comparison to existing nursing provision (chapter 2). Consequently, there is very little evidence available to inform future commissioners or providers on the current nursing

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element of service delivery and organisation for people with long term conditions living at home.

This study aimed to address these gaps in knowledge by identifying the range and types of nurse case managers and undertaking an in-depth description of their contexts, their activities, and their perceived impacts from the perspective of patients, carers, other service providers, and commissioners. Uniquely, the study compared and contrasted the experience of patients receiving different types of nurse case management over 12 months.

The literature synthesis (Chapter 2) identified that only nurses, and not midwives and health visitors, were involved in case management for long term conditions. It argued from the evidence in empirical studies of nurse case management that the work of the nurses in these roles could be categorised into three types of activity. The first type of activity was to **supplement** other services, often in order to address specific problems such as breaks in the continuity of service provision between primary and secondary care. The second type of activity was the **substitution** for another professional; usually, but not always, doctors. The influencing factors for these types of roles were mainly concerned with the relief of the medical workload through releasing expensive medical time from tasks that others could undertake. These categories are not necessarily exclusive; for example, the nurse case managers in the United Health Evercare model in nursing homes were both supplementing other services and substituting for doctors (Kane et al 2004). The last type of nurse activity was **complementing** other services, achieved by a mixture of clinical and technical work, psycho-social support, education, and navigation of the service; this type is provided alongside other services. There were few examples of this type of nursing activity but it appears that the primary influencing factors have been the organic, historical, or evolutionary development from within clinical services rather than responses to a single defined problem. A nurse becomes a case manager because of his/her long term contact with a patient's care.

We now consider the current influences supporting the development of nurse case management.

11.2 Influences stimulating the development of nurse case management models for people with long term conditions in England and Wales

In Chapter 3 the analysis of policies 2000-2007 identified 13 advocated roles for nurses in long term conditions management (LTC) in English policy and 7 in Welsh policy. A subsequent review of policies produced from 2008-2009, such as the Dementia Strategy for England (Department of Health 2008d), identified no other advocated activities and very few references specifically to nurses. The range of activities advocated for nurses, although not exclusively for nurses, in the English policies were much broader than those cited by commentators on chronic disease management models (Katon et al 2001, Rothman and Wagner 2003). This is explained, in part, by care system reform in England and policies directed at broadening occupational roles within health care (DH 2002b). It is

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most noticeable in the advocacy of nurses as case managers and the creation of the new community matrons' posts in England.

The policy review (chapter 3) identified that there was ambivalence in UK policy networks about nurse case management models. Whilst there were policy streams supporting new nurse case manager roles i.e. community matrons, there were also policy streams that did not refer to nurse case managers and suggested a variety of professionals could undertake this role (i.e. chronic conditions policies in Wales). Discussion of evolutionary models for existing generalist nursing services such as district nursing and practice nursing was absent in policy documents from England and Wales. The advocated named roles for nurses in providing care to people with LTC clustered in *substituting* for other health professionals, mainly doctors, and *supplementing for weaknesses in the system of care delivery* (section 3.1.3). The Welsh policy documents considered and rejected naming nurses specifically as case managers for people with LTC. In the English policy documents, case management roles were only advocated for nurses holding advanced practice skills qualifications such as independent prescribing or as specialists in a specific condition working alongside a medical consultant led team.

The national survey (section 3.3.) identified that the introduction of nurse case managers in English PCTs was driven by centrally monitored targets of the number of community matrons, following publication of policy guidance. In Wales central government direction and monitoring were absent and there was no introduction of these posts apart from in a pilot study conducted towards the end of this study (Huws et al 2008). Despite very specific guidance on the role of community matrons there were a wide variety of nurse case management models and nurse involvement in admission avoidance strategies for people with LTCs in England, (Chapter 3.3.3).

11.3 The range and types of nurse case management for people with LTC in England and Wales

The narrative literature review and synthesis (chapter 2), together with the survey (chapter 3) established that the term 'case management ' was not used consistently or used to refer to the same types of activities. Nurses were more usually identified as case managers when the posts they held were new or seen as innovative in some way. Established nursing services or nursing posts using case management techniques as part of established practice were rarely described in detail. In the survey, managers identified both new and established posts using case management techniques. This included nurses who were generalists and those who were specialists. The range of locations included attachment to general practice, consultant teams, social services, or working across a geographical area (section 3.3.6). The survey identified and confirmed the main groups of nurse case managers in primary care in England as: community matrons, clinical nurse specialists, and district nurses. In addition, the policy analysis and the survey identified variations e.g. nurse care managers working solely with care homes. The range of nurse case managers, the variety of their settings and work relationships was broader than that described before in the UK (Bergen 1992, 1994). This suggests that there has been an expansion of

nurse roles in primary care settings which mirrors that found in the UK in the acute sector during this period (Read et al 1999). There are a number of possible explanations for this variation, including:

- The local population and service needs are so different that multiple different forms of nurse posts are required,

Or

- That there is continual experimentation accompanied by little organisational learning on the characteristics of effective nursing roles that is shared across and between organisations or passed on to new managers in frequently reorganised primary care organisations.

The case study work in this research that took place in three very different populations and health economies indicates support for the second point of view.

11.3.1 Influences on implementing community matron policies

The employment of community matrons did not reach anywhere near the target numbers for 2008 (Keen 2008) as illustrated in Table 76. Central government monitoring of the PCT performance target of numbers of community matrons employed was withdrawn in 2008 (Healthcare Commission 2008). The evidence from the stakeholders in the case studies (chapter 11) confirms the ambivalence to nurse case managers also identified in the policy review. The analysis of stakeholder views and experiences also demonstrates local pragmatism and resistance in the face of the demands of the 'soft' bureaucracy (Courpasson 2000) of the NHS.

Table 76. Numbers of Community Matrons 2006-2008

Community matrons	2006	2007	2008
Headcount	366	619	1,521
Fulltime equivalents	351	571	1,422

Source: The Information Centre for Health and Social Care 2009b

The NHS managers and commissioners in the case studies presented in this report followed the central policy direction of developing community matrons but paid scant attention to the other groups of nurse case managers. The sidelining rather than development of nurse case management in generalist services, such as district nursing, was the result of repeated reviews, re-organisation and the removal from its ranks those with the most experience and advanced practice skills. Fulop et al (2002) showed that re-structuring and merging organisations disrupts services and service improvements, taking up to three years before the service is operating at the level or capacity it was before the reorganisation. The nurse case manager accounts in the case study phase (chapter 5) suggest that re-organising the structure of their services had similarly disruptive effects.

The evidence from the survey (section 3.3.9) and the case studies (section 5.2) demonstrated that there was not a ready supply of nurses with the advanced clinical skills to step into the community matron posts. In the main nurses were reported to come from within the district nursing service and then were trained

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while undertaking the community matron role (chapter 5). This lack of supply of advanced practice nurses, in part, reflects the long history of uncertainty in the UK as to the role, requirement for, and regulation of 'mid-level 'or 'advanced practice' health care professionals (Watson et al 1996, Nursing and Midwifery Council 2008). It also raises questions for local workforce planning in England where education for nurse registration is about to move from diploma level to degree level (DH 2006b) and there are subsequent shifts in nurses post-registration education frameworks (DH 2008e).

Pressman and Wildavasky (1973) suggest that implementation at local level of central government directives always results in variation through the dynamics of local power bases in decision making. The impression from the analysis at meso and micro level in the English NHS was not that there were powerful influences subverting the intention of the central policy,although that may have been true in some areas, but overall the multiple influences and contexts resulted in a more pragmatic approach to local decision making in the face of central directives. This pragmatic approach invariably led to local variation away from the centrally defined objectives.

11.3.2 Sustaining the innovation of community matron services

In none of the three PCTs were the innovations of the community matron service sustained or developed as initial planning suggested (chapter 4.6). Greenhalgh et al (2004) offered a conceptual model for considering the determinants of successful implementation and diffusion of innovation in health services. When the case studies are considered against the Greenhalgh model, it is evident that many features were missing in the implementation element alone. These omissions include slack resources in system antecedents for innovation, tension for change (i.e. agreement the problem was of such a scale that something needed to change) and supporters of the innovation were weightier than opponents in system readiness for innovation. The introduction and development of community matron services in all three PCTs were marked by shifting objectives for the service and discontinuities (Dawson 1995). Stocking (1985) argued that key factors in the adoption of innovation in the NHS included: the presence of identifiable enthusiasts for innovation or change, conducive power relationships (i.e. lack of conflict with national policies or professional opinion), a general perception that the innovation meets current needs and that there is minimal requirements for extra resources. Pettigrew et al (1992) identified that the receptiveness or not of local contexts was critical in the success or otherwise of implementing and sustaining change. In each case study site the enthusiastic champions for community matron services were only identifiable at the service level: i.e. those staff tasked with project managing the introduction and development of community matrons and the community matrons themselves (Chapters 4,5,10). The introduction of community matron posts in all three case study areas were resourced through existing nursing services so, while there was minimal use of extra services, the disruption and loss to other services created less that conducive relations with professionals such as general practitioners and the district nursing services. All the case study sites had mechanisms for monitoring the performance of the community matron service. These faced the

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impossible task of establishing a causal link between the creation of one role and a possible reduction in unplanned hospital admissions in over 75 years. The link between one role and reduced admissions was impossible. There were simultaneously multiple other service changes occurring in local health and social care services, e.g. developing new urgent care services, as reported in the PCT and Council Annual Reports of the participating PCTs. It was evident that by the end of the case study phase only a minority of stakeholders perceived the community matron service model, as meeting current needs (chapter 10).

11.4 The impact of nurse case management: the patients and carers experience

Many of the patients, and often the carers, in this study were considerably disabled by their conditions and some, as time progressed became frailer or died (chapter 6 and 9). A fifth of patients recruited died during the study period even though the nurses had considered that they were likely to be able to survive the data collection period of nine months. Some of the patients were being supported by spouse carer, many of whom also had LTCs and could be as equally frail.

11.4.1 End of life care

The tracking of the patient experience underlined that many of the older people receiving nurse led case management were either very frail, subject to multiple exacerbations of their LTCs and/or in the last months and year of life. Recent government initiatives have developed end of life care explicitly to include people with LTCs (Department of Health 2008f) however, our study showed that the transition from being an older person likely to benefit from case management to an older person in need of palliative care could be problematic, threaten continuity of care and create confusion as to who was the nurse case manager. Research on end of life care of people with end-stage COPD, and heart failure support these findings (Gibbs et al 2002, Yohannes 2007 Halpin et al 2008). Our study identifies a need for more work to be done on how the interface and transition between living with a long term condition and dying from it are addressed within current nurse case management models of care and primary care. This subject has begun to be considered in recent publications on end of life care in community settings (Walshe et al 2008, Bowler et al. 2009).

11.4.2 The aspects patients and carers valued from nurse case managers

All patients received multiple health and social care services and used these experiences to inform their judgements on what they valued in the nursing services they received from the nurse case managers. They judged the nurse case manager contribution (particularly the community matron and clinical nurse specialist) by comparing it to other medical and community nursing services on the basis of access, quality, and continuity of care. They identified three valuable aspects of the nurse case management:

1) The nurse had clinical expertise. This meant they could provide information and advice about particular conditions, help the patent gain confidence in self

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management and the early detection of exacerbations. In addition they could confirm whether a medical consultation was appropriate and in what timescale.

2) If required, the nurse was willing to be an intermediary between the person/ carer and health and social care services. This kind of intervention saved the patient and their carer time and ameliorated the aggravation and worry of living with a long term condition.

3) The nurse had a therapeutic effect because she was a source of psycho-social support and helped with access to a wide range of resources.

Carers

Our search of the literature, the policy review, and findings from the local survey found very little reference to the impact nurse case managers could have on the well-being of carers of people with LTCs. Carers with experience of the CMs recounted the attention these case managers paid to them. The case manager's attention to their anxieties and concerns, contrasted with their experience of other health care professionals. This is one potential outcome of effective nurse case management that has not been fully recognised in relation to people with multiple long term conditions. There is evidence that nurse care managers who focus on the needs of carers of people with dementia can reduce anxiety and symptoms such as insomnia in comparison to usual care (Woods et al 2003). Legislation and public service strategies to support carers (DH 2008g, Welsh Assembly 2007) recognise the need to support family and informal carers but primary care has not always been effective in delivering this. Recently commissioned pilots for education for GPs and for improving carer support in primary care are underway (DH 2009c). There has not been an exploration of the effect for carers of people with multiple LTCs and the impact for the broader health services. Evidence from this study may inform their development, determine questions to be answered and influence service commissioning.

Patient and Carer Identified Outcomes

Patients were able to specify the outcomes of nurse case management they valued:

- The patient (and carer) gained confidence in managing their condition, particularly early signs of exacerbations,
- The patient had learnt self management techniques that made their lives easier,
- The patient's <u>and</u> carer's priorities had been addressed,
- The patient's <u>and</u> the carer's, time and energy had been saved,
- There was continuity from a care provider who knew their 'story'.

Haggerty et al.'s (2003) systematic review identified three forms of continuity: informational, management and relational. They noted that processes such as case management do not of themselves equate to continuity but '*have to be experienced as connected and coherent'* (p.1220). It was evident that most of the nurse case managers who provided continuity in relationship to the patient (and carer) had to work hard to maintain continuity in other aspects i.e. information and management. Patients valued the nurse case managers but did

not expect other services to liaise with them. It was evident that information passed from the nurse case manager to GPs and consultants but there was very little evidence of information going the other way. There was also the paradox that the longer the nurse case manager knew the patient the more likely s/he was to delegate or refer the patient and carer to another nurse, nursing service or a less qualified practitioner.

11.4.3 The aspects patients did not value about nurse case management

Some patients were bemused to find themselves identified as the subjects of nurse case managers' attentions, an aspect of case finding activities noted elsewhere (Brown et al 2008). There was evidence that some patients of community matron case managers were concerned it was a form of public service surveillance. The tensions between proactive engagement from health and social care services being seen as a) 'surveillance' and a threat or insult to independence and b) of positive benefit in well being and aiding access to services has been described more commonly in relation to families and children (Dingwall and Robinson 1993, McKie 1995, Parton 1996). There is a critical theoretical literature that considers that health and social care services case management is a technical means for controlling older adults (Powell and Biggs 2000, Pickard 2009). It is not evident the extent to which patients and carers view case management as a mechanism of professional or state control. There is some evidence to suggest however, that many older adults assert and defend their independence and preferences by declining public service offers of support, financial assistance and services (Siddell 1994, Dant 1998, Drennan et al 2005).

11.5 The nurse case managers contribution to outcomes of care

This study, uniquely, compared and contrasted different types of nurse case managers (Community matrons, Clinical Nurse Specialists District nurses) who had a case management function for people with LTCs as all or part of their role. The case study phase of the research tracked the experience of a sample of older people with complex needs living at home, who were in receipt of nurse case manager services, over nine months in three case study sites. This study element addressed questions as to the categories of activities the different nurse case managers undertook with patients and carers, how this contributed to the structure, process and outcomes of care, and the impact this had on patients. In primary care settings through the experience of patients and carers prospectively followed over nine months.

The findings presented in chapters 6, 7 and 8 demonstrated that the nurse case managers irrespective of type could all identify they were undertaking the six elements of case management (described in section 1.3.1), however the frequency and intensity and cost (chapter 9) of using all elements varied between the types of case managers.

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11.5.1 Identifying patients (case finding)

All types of nurse case managers received patient referrals (chapter 6) from general practitioners and hospital services (both on discharge from in-patient care and after out-patient consultations). The DNs, CMs and care home case manager also received and accepted referrals of patients from social care and third sector organisations. Those who were actively 'case finding' (the CMs, the CNS and the care home case manager) diminished this activity over the period of the study. In doing this they reflect the evidence from single service and professional accounts of CMs (Russell et al 2009, Chapman et al 2009).

In contrast the level of nurse case manager to nurse case manager referral of patients increased over the time of the study. This is a mechanism that is rarely referred to in accounts of primary care for people with LTCs. This level of nurse to nurse activity has the potential to obscure the types and level of resource required to support people with LTCs.

11.5.2 Assessment, planning, implementation and review

The ways in which different types of nurse case managers engaged with the case management cycle varied, as detailed in the patient experience and the nurses accompanying accounts (chapters 7, 8, 9, 10). Only the community matron undertook all elements in their contact and involvement with patients. While the community matron patients had the highest co-morbidity, all the nurse case managers' caseloads had patients with equivalent needs. The CNS case managers focused on disease symptom and treatment activities. Only one of the CNS case managers started to move towards all case management activities with patients who were becoming frailer and more dependent on others. The care home case manager and nurse practitioner focused on assessing individual patients and referral to others without the elements of implementation and review. The interviews revealed how all the nurse case managers were adjusting their activities according to the volume of patient referrals and their perceptions of the presence of 'problems' they could help solve. Over the nine months of the study the nurse case managers who were engaging in all case management activities, sought to delegate or refer some of their patients to other nurses i.e. there was progressive disaggregation of the case management work. This is the first study to document the different levels of activity by nurses describing themselves as having a case manager function and the progressive disaggregation and dilution of the case management function overtime.

11.5.3 Nursing or nurse case management?

The six stages of the case management process, case finding, assessment of need, care planning, implementing care and monitoring and reviewing care are not dissimilar to how the work of nursing, and specifically community nursing is often summarized (White and Hall 2006, Drennan and Goodman 2007). Indeed the case management cycle has been part of the education for specialist community practitioners and embedded in their approach to their patients for some time (Drennan and Goodman 2005). The elements that differentiate the nurse and the nurse case manager are the extent to which she/he a) adopts and keeps a key worker role and b) maintains continuity of contact and care with the

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patient. In recruiting nurses who were established in their post and tracking their patients experience over nine months, this study was able to tease out what it was that the nurse case managers did, how the case management models of care differed and how the nursing focus and contribution changed over time. All the nurse case managers in this study either focused on certain elements of the case management process to the exclusion or others or by the end of the study had significantly reduced their case finding work and ongoing patient contact. It was within the discretion of the practitioner or the service how the case manager role was interpreted. It is to consideration of the factors that influenced that discretion that we now turn.

11.6 Costs associated with the nurse case manager activity

Case management when carried out by nurses who exclusively undertake this work is expensive. Data on service use over more than three months was only available for thirty three patients (chapter 9) and there are some caveats in that there were some differences in this sub-group compared to the overall group e.g. a higher percentage of men and lower numbers of prescribed medications. The mean monthly cost of nurse case managers per patient in this study is £302, but considerable variability was observed (SD 358; Range £8 – £1190). Consistent with smaller caseloads and exclusive focus on case management, community matrons provided greater input to their patients than did the other nurse case manager models. The main drivers of increased service costs were hospitalisations and intensive nurse case management contact. This may reflect that the intensive case managed patients were in fact towards the end stage of life. Evidence from the UK and North America demonstrates that the highest use of health and social care services are in the last year of life irrespective of age (Wanless 2002, McGrail 2000). Some, but not all of the patients receiving intensive nurse case management input reported lower use of other services. This together with the evidence of more referrals by CMs to other services raises the question as to whether case managers facilitate access to more services rather than prevent use of one service (an implicit policy assumption), as seen in the UK and some American demonstration projects (Challis et al 1991, Marshall et al 1999). More research is needed to establish what the extra benefits associated with the extra costs and resolve the related question of what is the optimal case load for nurse case managers.

11.7 Factors sustaining or inhibiting the models of nurse case management over time

The factors enabling and inhibiting the development of community matron services are discussed above (section 11.2). It is, however, worth reflecting on what are the factors that contributed or inhibited the nurse case managers' activities in all groups. The list of factors that supported the nurse case managers would probably reflect any change management or organisational development theorists' invocations: training for the role (knowledge and skills in classroom and practical settings), clinical mentors, managerial support, a defined

change management process to introduce new elements and supportive colleagues. It also included four other elements:

- A mandate to undertake case management activities, recognised by others providing or commissioning services to those patients,
- A close working relationship (including sharing patient records) with a multidisciplinary team, including the GP or consultant,
- Advanced clinical skills,
- Designated time for case management.

Table 77 describes how these elements were experienced by the types of nurse case manager and suggests that the balance between these factors inhibited or facilitated the contribution of the different types of case managers.

Table 77. Key factors influencing the nurse case managers' contribution to patient care by type of case manager.

	Mandate for case management	Close working relationship with MDT	Advanced practice skills	Time allocation for case management
CMs	Employer mandate but only some GPs	Only in some cases	Yes	Yes
CNS	Some had mandate from employers and some from consultants	Yes	Yes	Only for symptom management
DN	Some had mandate from employers	Only in some cases	Some but not all	Limited
Nurse practitioner	Partial from employer	Yes	Yes	Limited
Care Home Care manager	Employer mandate only	No	Yes	Yes

The preferences of the nurse case managers themselves were also influential. They all reported that personal and job satisfaction derived from direct patient contact and in particular contributing to 'problem' solving to improve a situation. We suggest that there is evidence for the converse i.e. the nurse case managers found little satisfaction in working with patients where there were no 'problems' to solve or where the problem was a slow decline in well-being and independence, only occasionally punctuated by episodes of acute ill-health. Nurse case managers reduced contact with people whose condition or situation showed slow decline. These were the patients they referred to another type of nursing service or delegated to a less qualified member of staff to hold a 'monitoring' function. The conundrum facing primary care services which engage in proactive case finding by clinically expert staff, followed by problem solving through relationship building is how to maintain and justify the relationship with the clinical expert person in the face of competing demands for limited resources (in this case clinically expert individuals). These tensions are not new in the search

for improvements in primary care for older adults (Iliffe and Drennan 2000) or in the provision of social work care management for older adults (Lymberry 1998, Challis et al 2001, Manthorpe et al 2008) but current policy interest in the needs of people with LTC provides an opportunity to revisit some of these tensions.

Linked with preferred type of interaction was the constant micro-level resource management of the nurse's own time in the face of a changing patient caseload and other work responsibilities. The district nurse case managers were supervising the delivery of care to considerable numbers of patients via large multi-skilled teams (chapter 5). The demands of first line management on that team, combined with repeated re-organisation, and staffing vacancies served to pull the district nurse case managers away from direct patient care. The phenomenon of the most educated and experienced nurses moving away from direct patient contact has been noted before (Davies 1995). The debate as to whether skilled staff should spend their time managing less skilled or transient staff rather than delivering care themselves will be returned to below.

The last point we consider is one that has not been addressed elsewhere. This study identified in all sites that the district nursing service was subject to repeated reviews and re-organisations. The context for the district nurse case managers was one of fairly constant disruption i.e. of the staff in their teams , of which GPs they were working with and as a consequence which patients, and thus with which adult social care staff and social workers. The search for the most efficiently and equitably configured district nursing teams appeared relentless in these sites over the study period. These sites are not alone in the experience of reviews (Drennan and Leyshon 2006) but the continual process of re-organisation and some of its consequences have not been documented before.

We turn now to consider the findings in the context over the overarching theoretical frameworks.

11.8 What kind of nurse, in what kind of setting, achieves what kind of outcomes?

The research questions and objectives of this study can be summarised by the question: what type of case management, delivered by which type of nurses, in what types of settings are effective for which patients? This framing of the question draws on the assumptions of realist evaluation and synthesis (Pawson et al 2005). Instead of asking whether nurse case management per se works, this study asked if nurse case management achieves different patient outcomes when it involves different nurses working in different contexts. Table 78 summarises this analysis. We argue that the context (the organisational environment, professional priorities, stakeholders involved, caseload size, and the process of implementation) combined with the mechanism of case management overwhelmed and constantly re-shaped and redefined what the nurses were able to achieve as case managers. By tracking how the nurses worked over the nine months, we showed that one model of nurse case management which started as wholly focused on case management (community matrons) changed over time as the nurses absorbed wider responsibilities. This

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model mutated to one where case management was only one part of a larger work brief and patient caseload interaction.

The questions remain:

- How these types of nurse case management fit with our understanding of systems of service delivery for people with long term conditions?
- What are the most effective divisions of labour in primary care systems of delivery, and from whose perspective?

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Table 78. A context, mechanism, and outcome analysis of types of nurse case managers with patients with long term care.

Case manager model	Context	Mechanism	Patients most likely to benefit
Clinical nurse specialist disease management with elements of case management Substitute	Working with GPs by negotiation Advanced skills in medication management	Case management with an emphasis on assessment and symptom management	Patients in the middle stage of their condition able to attend clinic, with complex health needs but limited access to specialist medical advice
District nurse case manager transient role as case manager Complementary	Embedded in primary care organisation	Case management with an emphasis on care provision of people with complex needs within a larger caseload	Patients with on gong complex needs where continuity of support and input important
Community matron case manager: Dedicated case manager Supplementary	Investment in role but mandate changes not recognised as key worker , working with permission	Case management Advanced skills in assessment and medication management	Patients with complex and fluctuating health care needs who do not “fit” with existing service provision whose health and social care needs are interlinked

11.9 Nurse case management , chronic disease management models and integrated services

The policies in the UK all use forms of a LTC population stratification triangle, sometimes known as the Kaiser Permanente triangle (DH 2005b, Welsh Assembly 2007b). The evidence from this study suggests that the use of this form of conceptual stratification in operational services terms is unhelpful. As with all models it represents a simplification that obscures the issues. It is an example of an organisational tool that would benefit from input from a clinical service delivery perspective. Those patients at the top level in the case studies had fluctuating health that technically moved them between strata. The strata were used to determine eligibility to certain forms of expertise. A patient’s changing health status therefore gave *permission* for the case management service to step back whereas the overall health trajectory was downwards and the patient perspective looked for relational continuity in care provider not being passed to other staff groups. The evidence would suggest modifications to the population stratification model, based on the increasing levels of experience in the UK in service delivery design for people with multiple long term conditions.

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This study confirms other evaluations that have highlighted that case management is unlikely to reduce hospital admissions (Gravelle et al 2007). There is a growing consensus that it was always an unrealistic aim to think that case management alone would reduce unplanned hospital admissions. Case management interventions need to be integrated with other primary care based initiatives (Shortell et al 2004, Ham 2009). Our study confirmed this need for integration and demonstrated the difficulties nurse case managers encountered when operating without a multi disciplinary (including medical staff) team as support. It also highlighted that nurse case managers with an appropriate mandate can act as a force for integration, continuity of care and effective collaboration between very disparate professional groups and organisations.

11.9.1 Do case managers with people with long term conditions have to be a nurse?

Several reviews and discussion papers on the contribution of case management to the care of people with LTCs, have acknowledged that whilst nurses may take on case manager responsibilities it is not clear if the role *has* to be taken by a nurse (Singh and Ham 2005, 2006 Sheaff et al 2009). Our reviews of policy and literature and the survey confirmed there was a lack of consensus about the contribution of nurse as case managers to chronic disease management. In addition our investigations identified the negative consequences for the service and front line practitioners, while this lack of consensus manifested itself in repeated service redefinitions and constant renegotiations of relationships. Competing pressures from LTC policies (and specifically the introduction of community matrons) were superimposed on established ways of providing care. This created a dissonance between policy and its implementation. Our case study phase further demonstrated that it was left to the discretion of different professionals to interpret and modify their case management work to fit with local needs and resources. Managers and nurses customised their case management work to reflect their own priorities and understanding of the process. Others have suggested that this local variation in England on the care and support of people with LTCs is a consequence of a lack of regulation and consensus about how to deliver services to people with long term conditions (Nolte and Mckee 2008, drawing on the work of Singh and Fahey 2008).

All three phases of the study highlighted how nurses were actively recruited and involved in supplementing for service deficiencies or compensating for other (medical) practitioners. This would suggest that a nursing qualification is essential for case managers to be able to achieve this and navigate and engineer the service to ensure that their patients access and receive care that is tailored to their needs (Forbes and While 2009). Indeed a greater recognition and affirmation of this work could help to define the nursing contribution more clearly (and as the patients in this study identified) as enablers, advocates and intermediaries in an imperfect system. It would create a strong mandate for nursing and address the ambivalence that some of the nurse case managers expressed about whether they were actually providing nursing care. If, however, the nurse case manager's major contribution is to compensate for the deficiencies of other parts of service delivery by substituting for doctors and supplementing services it could mean that nurses are just shoring up a failing

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system and masking its deficiencies. It also raises questions about the division of labour in primary care and the resource consequences.

11.10 The organisation of work in primary care

Primary care poses particular challenges to the organisation of services (chapter 1). Debates continue as to the efficiency and effectiveness of introducing new skill- mixes, new roles and creating hierarchical teams within the same professional groups (Peckham and Exworthy 2003). The in-depth case study phase revealed the segmentation of work between different types and grades of nurses, resulting in examples of the individual patient and carer receiving multiple nursing services. The evidence from the study raises the question as to whether this offers the most efficient and effective use of resources. This is a particular issue when considering services that are delivered in the home. Travel between patients' homes and office bases accounts for a significant amount of resource in these types of service, duplicated journeys more so (Audit Commission 1999). Our study suggests that the dominant Taylorist thinking that has led to larger district nursing teams with greater numbers of skill-mixed staff (i.e. more lower grade nurses and unqualified staff) has reduced the capacity of district nurses to sustain their work as case managers for those on their case load most likely to benefit from continuity of care. The introduction of community matrons, not only demonstrated a further segmentation of work, but distracted resources at the expense (both financially and in expertise) from the district nursing service.

Community nursing services in the NHS have been funded based on historical allocations (Hurst 2005) and have reflected the wider inequitable distribution of funds in the NHS (Webster 2002). The resourcing model in recent years has in the main followed the redistribution and allocation of the 'existing resource cake' between teams covering general practice in order to achieve greatest possible equity of workload and spread. Demand side resourcing models for district nursing, or more broadly community nursing, have not been evident in the NHS contracting and commissioning processes (Allen 2002, Hurst 2005). The new attention on developing 'commissioning currencies' and tariffs for community health services (DH 2008 c) as well as practice based commissioning (DH 2006) may provide the opportunity to explore and build new local resourcing models. It was evident from the case study sites that nurse case manager roles that evolved organically from the local clinical service delivery experience were sustained over time in ways that centrally determined posts were not.

We suggest that there are a number of questions raised by our discussion that could be investigated in future studies and have outlined them in box 1.

Box 1

Issues for further investigation:

- The fluctuating health service needs of frail, older community dwelling populations and the extent to which case management mechanisms e.g. through general practice, address the fluctuations over time,
- The contribution and impact of case/care managers from different professional backgrounds e.g. allied health professionals, to supporting people with multiple LTCs,
- The factors that support or inhibit the commissioning and provision of dedicated nurse case manager time within different networks of primary care,
- The extent to which nurse case managers (and other professionals in case manager roles) aid integration in primary health care systems and networks of care,
- The factors that enable an organisational memory, collective learning and knowledge mobilisation in service managers and commissioners for workforce design in service delivery for people with LTC,
- The development of service and patient outcome measures that fit with different case management models,
- The development and testing of regulatory frameworks for the care and case management of people with complex need,
- The relative value for money of the different types of nurse case management.

11.11 Conclusions

The findings from this report are timely as there is renewed interest in the contribution of nurses to patient care and the support, as well as the education they need to fulfil these roles. In March 2009 the government launched a new commission of experts to advise the Government on the future role of nurses and midwives to consider how nurses can improve safety, champion high quality patient care and give nurses the power to manage, commission and run their own services.

The Department of Health as part of its Modernising Nursing Careers policy agenda (DH 2006, 2008e) has predicted that the future preparation of nurses needs to be 'flexible and principle-based built around patient pathways with a strong academic foundation and interdisciplinary learning.

This multiple elements in this study demonstrated three important findings:

- Firstly, that the nursing contribution is invariably used to compensate for the shortcomings of other services and the fragmentation of health and social care services,
- Secondly, that the nursing role is subject to constant change and modification that often moves the practitioner from being a case manager to a position of care coordinator and clinical leader and

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- Thirdly, from a patient and family carer perspective the service is better and provides them with greater confidence and continuity of care when a nurse is able to work as a case manager,.

We summarise our recommendations in Box 2 .

- **Box 2**
- **Recommendations for Policy Makers**
- Recognise that continuity in care provider and provision is a key patient focused outcome for this population group
- Affirm the importance of the key worker role in community nursing positions and create the resource, training and support and infrastructure to enable nurses to fulfil this role
- Invest in strategies that explain to people with long term conditions how they can benefit from having a nurse case manager
- Address how strategies to support people with long term conditions using case management approaches interfaces with end of life care strategies
- **Recommendations for Service Commissioners and Providers**
- Develop a commissioning briefs and service level agreements that make explicit the intrinsic heterogeneity of the primary care nursing workforce, the differences between case management and disease management, and the minimum level of expertise required for nurses to work as case managers.
- Specify what kind of nurse case management is required for different patient populations and make explicit where the service is supplementing other services and working to integrate provision across the primary care organisation
- Provide nurses with a mandate and infrastructure to work as case managers for people with long term conditions
- Develop strategies that support nurses with case management responsibilities as part of a larger caseload to retain this element of their role
- Locate nurses working as case managers with named GPs and or medical consultants and establish a network of service provision and infrastructure (including shared documentation and budgets) that recognises and values the nurse case manager role and contribution as the patient's key worker
- Address the consequences of skilled clinicians becoming involved in human resource management and not case management and the risk that patients lose continuity of care and receive an increasingly fragmented service
- Address the priorities of older people for continuity of care, expert and accessible support that are responsive to their needs and fluctuating experience of health.

Many of the factors identified here as supporting or inhibiting the delivery of nursing services were not specific to nurse case management of people with LTCs. Previous research into the delivery of community nursing services to people with chronic disease/long term conditions has pointed to the significance of the of the service context, the importance of professional relationships within networks of care and the tendency of nursing services to privilege activities of

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assessment and treatment over activities of co-ordination and the management of uncertainty and frailty (see for example Hockey 1972, Kratz 1978 Badger et al 1988 Ong 1991 Smith et al 1993,Walshe et al 2008). However, our findings suggest that this privileging of certain types of work reflects the wider context in which nurse case manager role is a contested one, negotiated to fit local circumstances and professional priorities. We suggest from our findings that these issues will persist unless the nurse case manager is aligned more closely with a multi disciplinary team that recognises and affirms the nurse case manager role.

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Appendix 1 User Reference Group

Example of working methods and input

Details of the user reference group activity are given in full in chapter 1. This example of the working is from the third meeting. The group were presented with three vignettes from the study participants and asked to comment on the role of the nurse case manager and help analysis the data.

The vignette of TONY– (not his real name)

Summary:

Tony is 74, lives with his wife Margaret who is his carer. He has a history of respiratory disease. He had been seeing the community matron for 5 months and was referred to her by the hospital respiratory team.

Tony's health problems and their impact: Tony developed a lung condition known as Chronic Obstructive Pulmonary Disease (COPD) after exposure to asbestos at work. His condition has gradually deteriorated in the last six years or so since he retired. In addition to COPD, which is his main health problem, he has heart disease and liver cirrhosis.

He describes the main symptoms as: a heavy feeling in his chest, breathlessness and phlegm which is difficult to get rid of. His mobility is limited. He can walk to the bathroom, but needs to have someone there in case he gets unsteady on his feet. He also wheezes at night so he gets little sleep just 'catnaps'. Tony can do very little for himself since any exertion 'starts his chest off' and makes him breathless. As a result Margaret assists him with all his personal hygiene, dressing etc and ensures he has his nebulisers and other medication. He has been unable to go out of the house independently for the last four or five years.

Tony has had some adaptations to the flat including handrails and a bath rail, but does not receive any services from social care or the voluntary sector. Their application for a taxi card was refused and they have since decided it's not worth the trouble of applying for anything else, so they try to be self sufficient.

Living circumstances: Tony and his wife usually live in a rented flat with a lift, and have been living in the same area for at least 20 years. However, when they first joined the study they had been in temporary accommodation for the last six months following a fire in their own home. Margaret works part time nearby, but Tony is never left alone for more than an hour as their son stays with his father after he finishes work until she gets back. They have three sons who take them to appointments and help them out with transport generally.

Tony's experience of his health problem: Tony gets frustrated that he can't do as much as he'd like to and has been unable to write for the last two years because his hand shakes. He has a lot of knowledge about this condition and how to cope with the episodes of increased breathlessness he gets. He was very frank about the fact that his condition will only get worse in the future. His main

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priority is to manage his health problems at home so that he can stay out of hospital. He sees his GP very rarely and has six monthly follow up appointments with the hospital respiratory consultant. He uses no other health services.

He had six admissions to hospital because of breathing difficulties in the 12 months before he was referred to the community matron. In the four months since our researcher first met him, he has had several similar episodes of breathing difficulties (one was quite severe and he was in bed for 10 days) but none of which resulted in a hospital admission.

4. Margaret's experience of being a carer for Tony: Margaret is 62 and is in good health. Tony and Margaret say that they have a very close and supportive relationship, with a lot of humour which they say gets them through the difficult times. They have been together for 40 years. Margaret used to call 999 if Tony became breathless and unwell as the GP would not come out to see him. Since he has had a community matron she has not needed to do this as she calls the community matron instead and has an emergency prescription for antibiotics and steroids which she can use if the community matron advises her to. Margaret says the community matron is 'a godsend' and gives her a lot of support, which Margaret feels takes a lot of the pressure off her. Margaret feels that having one to one care for her husband from the community matron makes a big difference, and he looks forward to her visits.

Nurse's role in their care: The community matron says that she has a good relationship with both Tony and Margaret. She provides emotional support for Margaret and gives Tony both direct care and education about his condition, as well as emotional support. She visits once a week if his breathing is stable and stays for about an hour; twice or more a week if he is having an episode of breathing difficulties. Tony uses a telemonitoring device daily to record his blood pressure, temperature and oxygen saturation, this information gets sent directly down the telephone line to the community matron each day. The measurements give her an indication as to whether or not his condition is worsening, in which case she will call him or visit if necessary. When she visits, after asking him how he is feeling and assessing his chest and breathing, she checks that he has no other problems. They have worked out various strategies to assess whether or not he might be getting more breathless than usual. For example, working out the number of steps he can take before he gets breathless, any decrease in this usually means that his condition is worsening.

The community matron says that she has prevented Tony going into hospital at least twice by monitoring his condition in this way.

The discussion arising from Tony's experiences focussed on the following:

Not typical: Tony was described as 'one of the lucky ones'; he was not seen as a typical example of some one living with a long term health problem because he has a younger wife carer who lives with him, plus a local supportive family . He also received an unusually high level of contact from a nurse in the home (a community matron). The group thought that this was unusual and the result of 'postcode lottery'.

Lack of other social contact: Tony's apparent lack of social contact beyond his home and family was highlighted, since he hasn't been out independently for

about five years which was described as 'soul destroying'. The discussion centred on the way in which his situation may be affecting his psychological well being and consequently his physical wellbeing, if he was depressed and whether or not the community matron will have assessed him for this.

Fear of hospitalisation: The reasons for his fear of being admitted to hospital were also speculated on; including the possibility that his wife may also be fearful of him being admitted in case he doesn't come out. Reports of hospital acquired infections such as MRSA were thought to contribute to people's reluctance to being admitted.

Impact on his wife: His wife was described as 'a saint' since she does not appear to have any respite apart from the support she gets from the community matron. The group raised the question as to whether this couple knew about or had been assessed for social support. It was felt that the caring burden on her should be eased, and that she should be given more support from social services such as a home help. However, it was not certain that he would be entitled to this as the criteria varies in different parts of City site and this service is not free now.

The importance of remaining independent: The group discussed how remaining independent of others was very important to many people. A greater use of services may be seen by some people as an indication that they have lost control over their day to day life. 'There are more things in life than just your health'. Not everyone wants to have someone coming into their home; hence they may not accept help unless they are desperately in need.

Role of the GP: Tony's GP was described as 'invisible' because of their apparent lack of involvement in his care. It was thought that the GP should visit him at home and be more proactive in his care. The community matron was seen as a substitute for the GP in Tony's case.

The vignette of JANE – (not her real name)

Summary:

Jane is 73 , lives alone in a ground floor flat and has a history of heart failure. She was referred to the cardiac nurse specialist six weeks ago by the cardiology consultant following a hospital outpatient's appointment.

Jane's health problems and their impact: Jane says that she has had a defibrillator fitted two and a half years ago following a diagnosis of heart failure. She had been having difficulty breathing at night, and it was discovered that her heart was not functioning properly, so fluid was building up in her lungs. Initially her GP thought that she was having panic attacks so there was a delay in her diagnosis. Unfortunately, she had an infection after the first defibrillator so had to have a second one inserted. The main impact of the heart failure is that she gets breathless if she is hurrying or going uphill. She also has low energy levels and less stamina than she used to.

In addition, to heart failure she also has high blood pressure and high blood cholesterol which are controlled with medication, and overactive thyroid for which she had radiotherapy for and now takes medication. She also has gout in two of her fingers which gives her intermittent pain which is relieved with painkillers.

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Around the time that she developed the heart condition, she also experienced the bereavement of three close relatives within a short space of time, and subsequently became depressed and is taking anti-depressants.

The main effect of her heart problem is that although she does the same things as previously she does less of them and does them much more slowly. She still supervises some art students at home, and has recently had an art exhibition but it took her much longer to get her house back to normal afterwards than it used to. There has been no change in her social activities; she goes to a French lesson every week and has lunch with her friends afterwards.

Jane has seen the cardiac nurse specialist twice since she was referred to him. She sees her GP when she needs to and has six monthly appointments with the cardiologist at the hospital. She has also recently been seeing a podiatrist for a sore toe. If she had a problem with her health, Jane said that she would contact her GP in the first instance, and friends or neighbours for any other needs such as shopping.

Living circumstances: Jane has lived alone since her husband died, but says that she never anticipated that she would be living alone in her retirement, 'I'm lonely in the sense that I didn't mean to be a widow'. She is independent with all her shopping, cooking, looking after herself but has a private cleaner who comes once a week which she organised herself. She has lived in the area for 40 years and in this flat for 20 years, so she knows a lot of people in the local area.

Following three recent family bereavements, she only has two cousins who are alive but she is not close to them and does not have much contact. She has some family in another country but most of her regular contact is with friends or work colleagues. She has a work partner who she sees weekly, they also check up on each other every day. If she doesn't meet up with someone then she will always talk to a friend on the phone every day. She also has two good neighbours who check on her and will get her shopping if she's ill.

Jane's experience of her health problems: Jane says that having a heart condition has made her acutely aware of her vulnerability and her own mortality. These days she finds that she sits and rests a lot staring into space and is not sure why, 'Its set me on this way of thinking, I don't know how much this sitting staring into space is just laziness'. She also says that she feels that she has lost control over her life since she became ill this, and lacks motivation to get up and do things. Following the bereavements she saw a counsellor, but does not feel that she needs to see one now and thinks that she is getting better.

Nurse's role in their care: Jane has seen the cardiac nurse specialist twice since she was referred to him, once at home and once in the clinic. At each appointment he took her blood pressure, examined her chest, assessed her breathing and coughing, and took blood to monitor her medication and see whether the doses needed changing. He has not given her any health education about her condition as such, apart from advising her to stop drinking in the evening. 'I get too depressed in the evenings, the solution seems to be to have a drink or two or three, and I wish I didn't to it and I regret it, but I still do it'.

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If she had a problem with her health, Jane says that she would contact her GP she had not thought of contacting the nurse specialist as an option if she had a worsening of her heart condition, but thought that it would be useful to do that.

The discussion arising from Jane's experiences focussed on the following:

The role of community matron and nurse specialist: Differences in the role of the community matron and nurse specialist were highlighted for the group. Nurse specialists get most of their patients from the hospital consultant, whereas community matrons also get theirs from GPs, district nurses and other professionals. Community matron referrals fit specific criteria; their patients have complex health needs and frequent hospital unplanned hospital admissions prior to referral, whereas the nurse specialist's patients are referred for management of a specific condition. Unlike the community matron, nurse specialists are not a universal service and may have a larger caseload so that they are unable to get involved with people who have more complex health needs.

Mental health and long term health problems: The positive aspects of Jane's depression were discussed, in that she is still doing her usual activities even though she talked of having 'a loss of control'. It was suggested that her anti-depressants may need to be reviewed and that cognitive therapy may be beneficial for her. The nurse specialist's advice that she should stop drinking in the evening was seen as potentially unhelpful, and something that needed to be balanced against its use as a possible coping mechanism.

GP attitudes towards nurse specialists: The possibility that there could be of a clash of roles between the GP and nurse specialist was also discussed. This may result in some patients being worse off than if they did not have a nurse specialist.

Adapting to a long term condition: The group felt that it was difficult to clarify Jane's situation 'she can't quite make up her mind where she fits in and doesn't want to accept help'. However, it was acknowledged that it takes time to adapt to having a long term health problem, and in Jane's case also bereavement and the ageing process. It was suggested that there is a tendency to medicalise these events even though 'this is all part of life'.

Maintaining friendships through ill health: The fact that Jane had managed to hold onto her friendships despite her ill health was seen as admirable. People face different challenges in relation to their health problems depending on their age; younger people with long term conditions may find it more problematic to maintain friendships.

Impact of having a carer: The possible impact of having a carer on the services received was discussed, and whether or not this would improve their access to and experience of health and social care.

Barriers to accepting help: The older people in these examples are from a generation where reliance on the welfare state was stigmatised, hence they may be reluctant to apply for services on top of the hassle of the associated form filling.

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IRIS – (not her real name)

Summary:

Iris is 80, lives alone in a warden controlled flat, has a history of asthma and has recently been diagnosed with the lung condition COPD. Her GP referred her to the community matron after Iris refused to go to hospital during a number of severe episodes of breathlessness. She has been seeing her for three months.

Iris's health problems and their impact: Iris has had asthma for 30 years, but it has become a lot worse in the last few years, and she has recently been diagnosed with COPD at the hospital outpatient's clinic. Iris also has heart disease and brittle bones, but her main problem is the episodes of severe breathlessness that she gets which she refers to as 'asthma attacks' .These happen at any time and recently happened twice when her sister was staying, once while they were out which was very distressing.

Her mobility is limited by her breathing difficulties; she says that she can get around the flat but can only go out in a wheelchair so she has to rely on someone to take her out. She is fine when sitting but becomes breathless if she starts using her arms to do anything. Iris also has to use oxygen when she is sleeping, but normally sleeps well. Occasionally she wakes up breathless which makes her very anxious. Her hands have also recently started shaking, so she says that she finds it difficult to write.

She sees her GP when necessary. She no longer sees the smoking counsellor (who helped her stop smoking habit of 64 years last year) or the hospital consultant, who has sent her an information sheet about COPD which she said, did not make much sense, so she was going to discuss it with her community matron

Living circumstances: Iris lives alone and has been in the area for a long time, so she has a lot of friends and neighbours who call in or phone regularly so she always sees someone every day. Her sister lives in another country and visits twice a year and stays for a month or so to look after her. Her son lives outside of London but visits when he can; he phones her at least twice a day. She says that she also has a good relationship with the warden who visits her at least once a day, and also attends the local community centre twice a week for lunch and social activities. On Fridays she uses a shopping bus organised by the council, they provide her with an electric wheelchair. She also has a taxi card so she takes a taxi if she needs to go to the bank or somewhere. They are prompt to collect her but sometimes leave her waiting for up to two hours when picking her up so she doesn't like using this service. Iris deals with her personal hygiene, dressing, and meals herself.

She has a private cleaner organised through Age Concern. However, she tries to do as much housework as possible herself, resting frequently during activities. As she says 'I can get on with it, do little things, sit down and then do some more'.

Iris's experience of her condition: Iris likes to be independent and says that she feels she is a burden now that she has to rely on people to take her out now, 'It's another thing that hurts; you have to ask people all the time; I like to be independent I think its unfair when I have to ask people and they say if ever I

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need something to tell them but maybe sometimes you don't want to, I'd sooner get up and do it myself'. She does not feel that she should phone the community matron for anything, but will contact the warden if she is unwell although she doesn't like to burden her either, and also has a Careline button for emergencies.

Nurse's role in their care: The community matron said that Iris has been offered lung surgery to address one part of her problems but she has refused, just as she has refused any hospital admission. According to the case manager, Iris is reluctant to go into hospital in general because of fears of contracting MRSA, but has a suitcase packed just in case she needs an emergency admission.

The community matron visits her once a week for about an hour and also phones her regularly to see how she is. When she visits she asks her about her symptoms, how her health has been and does a detailed assessment, examines her chest takes her blood pressure, oxygen saturation, peak flow[6] and encourages her to do deep breathing exercises when she feels breathless. The community matron arranged for hand rails, bath rails and a door intercom to be fitted, Iris says that she finds the community matron very helpful and does not want to see anyone else for her health problems apart from her GP. If Iris is having an 'asthma attack' the community matron has advised her to breathe in through her nose and out through her mouth, but she can't do it when she is breathless. 'She says take a hard breath in, but I say don't tell me how to breath'. She usually tries to sit and calm herself down if she feels she is having an attack and opens the window to let some air in.

A brief discussion of Iris's experiences is summarised below:

Not a typical example: The group felt that Iris's example was not typical of someone with a long term health problem. She was described as 'lucky' since she had a lot of supportive neighbours and friends, which was not thought to be a typical inner city situation.

Patient choice: The downside of the current emphasis on patient choice was discussed including, the difficulty of making an informed choice if someone is not aware of what they are entitled to. Some people may just want professionals to advise them rather than making a choice about something they know little about. 'How many people know what their rights are and what they are entitled to?'

Missing information: Where possible the following information was requested for future analysis of the patient experience: a)Financial situation of the patients and what benefits they are receiving such as, pension credit, b) Living circumstances and more detail on their geographical location and c) Reasons why patients refuse services

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Appendix 2 List of Policies

Policies listed by number as reviewed in chapter 3
1. Audit Commission 2000, The Way to Go Home: Rehabilitation and remedial services for older people, Audit Commission, London.
2.Audit Commission 2002, Integrated Services for Older People: Building a whole system approach to services in England, Audit Commission, London.
3.Audit Commission 2002, Forget Me Not: Mental health services for older people (Update 2002), Department of Health, London.
4.Audit Commission 2004, Older people - Independence and Well-being: A Challenge for Public Services , Audit Commission, London.
5.Audit Commission and Commission for Social Care Inspection and Healthcare Commission 2005, Living Well in Later Life -A Review of Progress Against the National Service Framework for Older People, The Stationary Office, London.
6. Care Services Improvement Partnership 2007, Older People's Involvement and Co-production, CSIP, London.
7 .Care Services Improvement Programme Older Peoples Mental Health Programme 2007, Strengthening the Involvement of People with Dementia, CISP, London.
8.Chief Nursing Officer. Chief Nursing Officer's Bulletin. July 2004 page 2. London, Department of Health.
9.Chief Nursing Officer 2000, Making it Happen: Integrated Working in Primary Care, Department of Health, London.
10.Commission for Healthcare Audit and Inspection 2007, The State of Healthcare 2007, The Stationary Office, London, HC 97.
11.Department of Communities and Local Government & Department of Health. 2007, Delivering health and well-being in partnership: The crucial role of the new local performance framework, Department for Communities and Local Government, London.
12.Department of Communities and Local Government 2007, Independence and Opportunity: Our Strategy for Supporting People, Department of Communities and Local Government, London.
13.Department of Health 2000, Effective Care Co-ordinator in mental health services, Modernising the Care Programme Approach - A Policy Booklet, Department of Health, London.
14.Department of Health 2000, The NHS Plan A plan for investment A plan for reform Cm 4818-1, The Stationary Office, London.
15.Department of Health 2000, National Service Framework for Cancer, Department of Health, London.
16.Department of Health 2000, National Services Framework for Coronary Heart Disease, Department of Health, London.
17.Department of Health 2000, Partnership in Action, Department of Health, London.
18.Department of Health & Home Office 2000, No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse, Department of Health, London.
19.Department of Health 2001, Fair Access to Care Services, Policy Guidance, Consultation Draft, Department of Health, London.
20.Department of Health 2001, Investment and Reform for NHS Staff: Taking Forward the

Policies listed by number as reviewed in chapter 3

NHS Plan, Department of Health.

21.Department of Health 2001, Making it Happen- A Guide to Delivering Mental Health Promotion, Department of Health, London .

22.Department of Health 2001, Medicines and Older People: Implementing medicines-related aspects of the NSF for Older People, Department of Health, London.

23.Department of Health 2001, National Service Framework for Older People, Department of Health, London.

24.Department of Health 2001, National Service Framework for Diabetes, Department of Health, London.

25.Department of Health 2001, Priorities and Planning Framework 2002/3, Department of Health.

26.Department of Health 2001, The NHS Plan: Implementation Programme, Department of Health, London.

27.Department of Health. The expert patient: a new approach to chronic disease management for the 21st century. London, The Stationery Office.

28.Department of Health 2001, NHS Funded Nursing Care Practice Guide & Workbook, Department of Health, London.

29.Department of Health 2001, Making a Difference in Primary Care: the Challenge for Nurses, Midwives and Health Visitors - Case studies from NHS regional conferences, Department of Health, London.

30.Department of Health 2002, Delivering the NHS Plan; next step on investment, next step on reform, The Stationary Office, London.

31.Department of Health 2002, Information Strategy for Older People in England, Department of Health, London.

32.Department of Health 2002, Liberating the Talents: Helping Primary Care Trusts and nurses to deliver The NHS Plan , Department of Health, London.

33.Department of Health 2002, Delivering the NHS Plan :next steps on investment, next steps on reform Cm 5, Department of Health, London.

34.Department of Health 2002, Improvement, Expansion And Reform: The Next 3 Years Priorities And Planning Framework 2003 - 2006, Department of Health, London.

35.Department of Health 2003, National Service Framework for Diabetes: Delivery Strategy, Department of Health, London.

36.Department of Health 2003, Implementing the NSF for Older People Falls Standard – Support for commissioning good practice, Department of Health, London.

37.Department of Health & Royal College of Nursing 2003, Freedom to practise: dispelling the myths, Department of Health, London.

38.Department of Health 2003, Building on the Best: Choice, Responsiveness and Equity in the NHS. Cm 6079 , The Stationary Office, London.

39.Department of Health. Improving Chronic Disease Management. 2004. London, Department of Health.

40.Department of Health 2004, The National Service Framework for Renal Services Part 1: Dialysis and Transplantation, Department of Health, London.

41.Department of Health, Older People Directorate. 2004, Better Health in Old Age - Report , Department of Health, London.

42.Department of Health 2004, Choosing Health: Making healthy choices easier . Cm

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Policies listed by number as reviewed in chapter 3
6374, The Stationary Office, London.
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45.Department of Health. 2005.Supporting People with Long Term Conditions: A NHS and Social Care Model to Support Local Innovation and Integration. London, Department of Health.
46.Department of Health. 2005 Self care - A real choice: Self care support - A practical option. . London, Department of Health.
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48.Department of Health 2005, The National Service Framework for Renal Services – Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care, Department of Health, London.
49.Department of Health 2005, Self Care – A Real Choice, Department of Health, London.
50.Department of Health 2005, Independence, Well-being and Choice: Our vision for the future of social care for adults in England .Cm 6499, The Stationary Office, London.
51.Department of Health 2005, NHS Business Arrangements: The Rules for 2006/7The NHS in England: the operating framework for 2006/7, Department of Health, London.
52.Department of Health. Our Health, Our Care, Our Say: A New Direction for Community Services. [Cm 6737]. 2006. London, The Stationary Office.
53.Department of Health 2006 . Our Health, Our Care, Our Say: Making It Happen. . London, Department of Health.
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55.Department of Health 2006. Caring for People with Long Term Conditions: an Education Framework for Community Matrons and Case Managers. London, Department of Health.
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58.Department of Health. 2006, A New Ambition for Old Age , Department of Health, London.
59.Department of Health 2006, The NHS in England: the operating framework for 2006/7, Department of Health, London.
60.Department of Health 2006, The NHS in England: the operating framework for 2007/08, Department of Health, London.
61.Department of Health. Choice matters 2007–08: Putting Patients in Control. 2007. London, Department of Health.
62.Department of Health 2007. Choice Policy Team. Generic Choice Model for Long Term

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Conditions. London, Department of Health.

63.Department of Health 2007, National Stroke Strategy, Department of Health, London.

64.Department of Health 2007, The NHS Continuing Healthcare (Responsibilities) Directions 2007, The Stationary Office, London.

65.Department of Health 2007, The Delayed Discharges (Continuing Care) Directions 2007, The Stationary Office, London.

66.Department of Health 2007, Choice Matters 2007-2008, Department of Health, London.

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Policies listed by number as reviewed in chapter 3
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87.National Institute for Clinical Excellence 2003, Management of chronic heart failure in adults in primary and secondary care.
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Appendix 3 Data collection tools: the nurses

This appendix presents a summary of the data collection tools used with the nurses in the study. The data collection process is presented in chapter 4. Full details of the tools can be obtained on application to the lead author (contact details in the front cover).

A 3.1 Nurse Interview at Baseline

Nurse interview 1: at the beginning of the case study focused on:

- Job roles and structures
- Case and workload
- Professional history
- Role and responsibilities
- Weekly diary sheet

Interview questions included the following plus a number of prompts:

1. How would you describe a typical working day?
2. Patient care. How does a patient become part of your case load?
3. Any time limits on how long a patient can receive care?
4. Is there a minimum or maximum number of patients you will have on your caseload? Homogeneity or heterogeneity of case load?
5. When you accept a patient on to your case load what are the first things that you will do?
6. When you provide and plan care for your patients what does that generally involve?
7. Where the care is provided?
8. How do you review and monitor the care your patients receive from you and other services?
9. Do you have any involvement with carers (if yes)
10. Organisational role and responsibilities?
11. Do you have access to a computer/email etc
12. Do you have administrative support, if yes how much?
13. Do you control a budget, if yes how much?
14. Apart from your patient related responsibilities do you have other responsibilities in the organisation (e.g. committee/representative work)?

15. Do you have other responsibilities outside of your employing organisation (e.g. university teaching, charities and voluntary groups)?
16. Who is your manager?
17. Do you have a mentor?
18. Would you describe yourself as working as part of a team? YES / NO
19. If you need clinical advice or support, who do you go to?
20. Apart from your team any other professionals that you have contact with as part of your work?
21. Please can you list the different organisations that you work with?

Nurse Information

1. What is your job title?
2. Who is your employer?
3. How long has this post been in the service?
4. How long have you been in your current post?
5. Are you full time? YES/NO
6. Is your contract permanent or temporary/fixed?
7. What is your age? 21-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐
8. How long have you been working as a qualified nurse?
9. What nursing qualifications do you have?
10. How would you describe your nursing background?
11. Community nursing, posts held, how long?
12. Acute nursing, posts held, how long?
13. Other nursing experience?
14. Can you tell me why you applied/chose to do this job?
15. Can you tell me what AfC band you are on?
16. Have you had any training that is specific to your current post?
17. Are you currently doing and further training or learning?
18. Are there any aspects that you think you need more training for?
19. Since you took up this post has the job changed?
20. What gives you job satisfaction and why?
21. What are the challenges and difficulties of this job?
22. Five years from now what nursing post would you like to have?

Request to fill in weekly diary sheet provided on next page

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ENCaM: Nurse Activity Diary. **Nurse code: ……………………….Week beginning…………………..…200__**

Day/ Time	Where? *(Clinic/ office home visit etc)*	Time spent *(Hrs,mins)*	Brief details of each activity. *(eg: visit to patient, correspondence, MDT meeting)*	Follow up required? *(Eg, letters, phone calls, referrals)*	Case management? *Yes/ No*
Mon AM					
Mon PM					
Tue AM					
Tue PM					
Wed AM					
Wed PM					
Thurs AM					
Thurs PM					
Fri AM					
Fri PM					

NB This is an example of key categories and level of detail planned for data collection – format, layout and medium to be used will be agreed with each nurse.

ENCAM nurse diary v1 21/05/2009 1

A3.2 Nurse Telephone interviews months 2-8

These telephone interviews took place once a month, in months two to eight of ENCaM. They focused on:

- Review of study patients
- Review of nurse experiences and opinion

Patient review questions

Patient code:

- How has this patient been in the last month: e.g. Changes in health, improvements/exacerbations/deteriorations, changes in treatment, Significant changes in social circumstances, major events/incidents in patient's life, hospital visits planned unplanned.
- What has nurse done for the patient? E.g. Types of care given (using triggers of assessment/care planning /co-ordination of services/direct care/review and evaluation, administration/related meetings, frequency of contact in the last four weeks, involvement with carer, Referrals (who to, reasons, referral pathways), equipment (what, how, sources, cost to patient, sources of funding).
- Patient service use? e.g. Changes to service use and reasons
- Case management related activities? e.g. Team meetings e.g. Multi professional team.

Having completed the above for the 5 patients then ask:

1. In the last four weeks what has given you gives you job satisfaction and why?
2. In the last four weeks what have been the challenges and difficulties of your job?

A3.3 Nurse interview 9: end of study

Repeated baseline data (A4.1 above) and study period review focused on

- Job roles and structures
- Case and workload
- Professional circumstances

In addition:

- How has your job changed in the past nine months?
- Has the way that a patient becomes part of your case load changed since the start of the study?
- What do you do for the patients you case manage and has this changed since the start of the study?
- How do you review and monitor the care your patients receive from you and other services and has this changed since the start of the study?

Thinking about your work in general over the past nine months:

- Are there any aspects of the job that you think you need more training for?
- What gives you job satisfaction and why?

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- What are the challenges and difficulties of this job?
- Five years from now what nursing post would you like to have?
- What are your strengths as a case manager/key contribution?

Case Management

Researcher: For the last nine months we have been asking you about five of your patients and the work you have done with them. Now we want to reflect on your role as a case manager as a whole.

- What are the opportunities and challenges of your role as a case manager?
- Who have been the most significant people in your role as a caser manager?
- How would you like to see your case management work develop?
- How long do you intend to stay in this post?
- Five years from now what nursing post would you like to have?

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Appendix 4 Data collection tools: the patients

This appendix presents a summary of the data collection tools used with the patients in the study. The data collection process is presented in chapter 4. Full details of the tools can be obtained on application to the lead author (contact details in the front cover).

A4.1 Patient Interview 1:

Note to researcher: this Interview has two parts:

PART A: A series of open ended questions which will be based on a guide to question areas with prompts for the interviewer to help in the collection of data. The aim of this is to allow the participant to have a conversation with the interviewer, so that the researcher can try to build rapport with them. The order in which questions are asked can be flexible, and questions should only be asked if they have not been answered previously.

PART B: A series of structured questions which will be completed by the interviewer with the patient, but which the patient may wish to see as well. You should use the question cards provided if the patient does want to see the questions or self complete.

The patient can stop the interview at any time if they wish, particularly if they become too tired or feel too unwell to continue. If you observe that the patient may need to stop for any reason you should ask if they wish to continue. You should also ask this between Part A and Part B. If the patient does wish to stop the interview at any stage, you should arrange a second appointment to complete the interview, if the patient is willing to do so.

Part A

Guide to question topics (NB each topic had accompanying prompts):

- How are you today?
- What problems do you have with your health?
- What medicines, aids and treatments do you have to help you with your health problems? Prompts formal and informal
- How do your health problems affect your life? E.g. Physical effects, psychological/emotional (attitude towards illness) , financial
- What kind of help do you need most for your health problems?
- Other help and support including transport, financial, information etc
- Living circumstances - Who lives here with you?
- Who else is important in your life?
- Do you have anyone who cares for you and who isn't paid for doing so?

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- Accommodation and finance (by observation where appropriate)
- Does patient have any problems with their accommodation?
- How does the person feel about the place and community they live in – security, social networks, isolation etc.?
- Income support/disability allowance received?
- Nursing care: What does your nurse do for you?
- Other help and support? What other services do you use to help you with your health problems?

Researcher: record services used, using table as a prompt:

Service type	Last contact	Frequency of contact	Reason for use	Location (Home/elsewhere? – where)
NHS consultant				
Private consultant				
Pharmacist				
Physiotherapist				
Occupational Therapist				
Community nurse				
Social worker				
Paid carer				
GP				
Practice nurse				
Counsellor				
Dietician				
Charity/voluntary services				
Hospital – outpatient				
Hospital - inpatient				
Other –				

- Who do you contact when you need extra help?
- Is there anything else that we have not talked about that you think is important?

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Part B :Structured data collection tools

Researcher:

Thank you for taking part in this study. The questions in this booklet are about you, your health and how you are feeling. The study researcher will go through them with you. If there is anything that is not clear, or you would like more information please ask. If there are any questions that you do not want to answer, please tell the researcher. We appreciate your time and help with this study.

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Researcher: Explains that the next section contains set questions that ask for specific answers but reinforces that the patient does not have to answer them and can stop the interview at any time. Researcher hands section B question booklet to the patient for them to look at, if they wish to see it.

1. **Demographics**
(Complete from records where possible)

a. **Gender** Male ☐ Female ☐

b. **Date of birth**? _____________ (ask for age if date of birth a problem)

c. **How would you describe your ethnic group?**
(Researcher: use a show card as prompt to help with answers?)

A White	
1.British	
2. Irish	
3. Any other White background, (specify)	
B Mixed	
1. White and Black Caribbean	
2. White and Black African	
3. White and Asian	
4. Any other Mixed background, (specify)	
C Asian or Asian British	
1. Indian	
2. Pakistani	
3. Bangladeshi	
4. Any other Asian background(specify)	
D Black or Black British	
1. Caribbean	
2. African	
3. Any other Black background (specify)	
E Chinese or other ethnic group	
1. Chinese	
2. Any other (specify)	

d. **First language** _____________

e. **What was your last experience of formal education?**

____

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SECTION ONE

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

1. Mobility

I have no problems in walking about ❑
I have some problems in walking about ❑
I am confined to bed ❑

2. Self-Care

I have no problems with self-care ❑
I have some problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

3. Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ❑
I have some problems with performing my usual activities ❑
I am unable to perform my usual activities ❑

4. Pain/Discomfort

I have no pain or discomfort ❑
I have moderate pain or discomfort ❑
I have extreme pain or discomfort ❑

5. Anxiety/Depression

I am not anxious or depressed ❑
I am moderately anxious or depressed ❑
I am extremely anxious or depressed ❑

Score
Total:

© EuroQoL Group 1990

Best imaginable health state

Researcher: Hands copy of thermometer to patient for them to complete or completes it with them.

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today

Worst imaginable health state

Score

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Researcher: Hands over patient copy of section 2 which is a user friendly unscored version

SECTION TWO

Function	Score	Description	Score
Bowels	0 1 2	Incontinent (or needs to be given enemas) Occasional accident (once/week) Continent	
Bladder	0 1 2	Incontinent, or catheterised and unable to manage Occasional accident (maximum once per 24 hours) Continent (for over seven days)	
Grooming	0 1	Needs help with personal care Independent face/hair/teeth/shaving (implements provided)	
Toilet use	0 1 2	Dependent Needs some help, but can do something alone Independent (on and off, dressing, wiping)	
Feeding	0 1 2	Unable Needs help cutting, spreading butter etc Independent (food provided in reach)	
Transfer	0 1 2 3	Unable – no sitting balance Major help (one or two people, physical), can sit Minor help (verbal or physical) Independent	
Mobility	0 1 2 3	Immobile Wheel chair independent including corners etc Walks with help of one person (verbal or physical) Independent (but may use any aid, e.g. stick)	
Dressing	0 1 2	Dependent Needs help, but can do about half unaided Independent (including buttons, zips, laces etc)	
Stairs	0 1 2	Unable Needs help (verbal, physical, carrying aid) Independent up and down	
Bathing	0 1	Dependent Independent (or in shower)	
		Total	

Simplified Barthel Scale

Barthel score	Level of dependency
0-4	Total
5-8	Severe
9-12	Moderate
13-16	Low
17-20	Very low

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Researcher: Hands over patient copy of section 3 which is an unscored version
6CIT – Six item Cognitive Impairment test (Kingshill Version 2000)

SECTION THREE

Tick all correct answers

1. What year is it? ☐
2. What month is it? ☐
3. Please remember the following address (5 components) ☐
4. About what time is it (within 1 hour) ☐
5. Please count backwards from 20 to 1 ☐
6. Please say the months of the year in reverse ☐
7. Please repeat the address you were given ☐

Score 1 for each correct answer

Total score ☐

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Researcher: Hands over patient copy of section 4

4 Item GDS Geriatric Depression Score

SECTION FOUR

The next questions ask how you are feeling about life at the moment, please answer yes or no

1. Are you basically satisfied with your life? Yes ☐ No ☐
2. Do you feel that your life is empty? Yes ☐ No ☐
3. Are you afraid that something bad is going happen to you? Yes ☐ No ☐
4. Do you feel happy most of the time? Yes ☐ No ☐

Score 1 for each "Yes" response

Total score ☐

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Researcher: Hands over copy of scale to patient

Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

Question	Not at all confident — Totally confident
1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	1 2 3 4 5 6 7 8 9 10
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	1 2 3 4 5 6 7 8 9 10
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	1 2 3 4 5 6 7 8 9 10
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	1 2 3 4 5 6 7 8 9 10
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	1 2 3 4 5 6 7 8 9 10
6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	1 2 3 4 5 6 7 8 9 10

Total score [ ]

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A4.2. Patient Telephone Months 2-8

Telephone interviews were conducted once a month in months two, three, four, six, seven and eight of the study. They focused on briefly repeating the questions in Part A of the first interview and probed for anything that might have changed or occurred.

The interview in month 5 was face to face and involved the questions of the telephone interviews plus repeating all the structured tools of part B of the first interview (detailed above).

Telephone interview Researcher:

Good morning/afternoon/evening. Is this still a convenient time for you to speak to me?

I would like to ask you some more questions about you, your health, how you are feeling, and about the nursing care and other services that you are receiving. This should take a maximum of ten minutes. If at any stage you need to have a rest or to stop and continue another time please tell me.

As usual, everything you tell me is in the strictest confidence and your anonymity will always be assured.

If anything that is not clear, or you would like more information, please ask. If there are any questions that you do not want to answer please tell me.

We appreciate your time and help with this study.

Topic areas

- Patient health and Euroquol
- Other significant events in past month?
- Nursing care in the past month
- Other usual services used
- Other visitors in past month/contacts/social activities
- New service/treatment/therapy use
- Other changes to services received?

Thank and make appointment for next call/face to face interview as appropriate

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Appendix 5 Data collection tools: the carers

This appendix presents a summary of the data collection tools used with the carers in the study. The data collection process is presented in chapter 4. Full details of the tools can be obtained on application to the lead author (contact details in the front cover).

A5.1 Carer Interview 1 and 2

First Interview was conducted face to face with carer at start of study. The following was the topic guide to the questions (NB each topic had accompanying prompts):

- Gender and age recorded
- Relationship to Carer
- What kind of care do you give this person?
- What support do you get in providing this care?
- Please can you describe a typical day for you?
- What does the nurse do for
    - The patient
    - The carer
- If (patient name) needs to see a doctor or to go to hospital, how much do you help to decide on this/arrange it?
- Apart from (patient name) are you carer for anyone else?
- Health - Do you have any health problems that affect what you can do for the [person you care for]?

The Carer Strain Index (without the scoring aid) was offered to each carer as given on the next page..

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The Caregiver Strain Index:

I am going to read a list of things that other carers sometimes experience. Do of these apply to you?

(Researcher hands over an unscored list, then goes through the list with the carer)

	Yes=1	No=0		Score
Sleep is disturbed (e.g., because ______ is in and out of bed or wanders around at night)				
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)				
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)				
It is confining (e.g., helping restricts free time or cannot go visiting)				
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)				
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)				
There have been other demands on my time (e.g., from other family members)				
There have been emotional adjustments (e.g., because of severe arguments)				
Some behaviour is upsetting (e.g., because of incontinence; ______ has trouble remembering things; or ______ accuses people of taking things)				
It is upsetting to find ______ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)				
There have been work adjustments (e.g., because of having to take time off)				
It is a financial strain				
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)				
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress)				

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Carer Interview 2

Topic area questions included:

- How has the care that you give to (patient name) changed since I last interviewed you?
- In the past 9 months what support have you had in providing this care?
- How services were organised
- Sources of information about availability of services
- Help used in organising services
- Respite care (formal and informal)
- Please can you describe a typical day for you?
- Percentage of day carer has without caring activity
- In the past nine months, what are the most important things that the nurse has done for:
    - The patient
    - The carer
- If (patient name) needs to see a doctor or to go to hospital, how much do you now help to decide on this/arrange it?
- What would make you decide that (patient name) needs to go to their GP, or to hospital?
- Nature of involvement in arranging appointments etc
- What influence does carer have in patient decisions)
- Apart from (patient name) are you now a carer for anyone else? ☐
- What kind of care do you give this person?
- What support do you get in providing this care?
- Do you currently have any health problems that affect what you can do for the [person you care for]?
- Repeats offering The Caregiver Strain Index
- If you think about what the nurse has done for [the patient] and for you in the past nine months, what have the most important aspects of this been for you?

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Appendix 6 Patient Timelines over Nine Months

Examples given relate to text in chapter 6 and chapter 8

Patient 3 Community Matron as case manager

Patient profile: Male, 91,Lives alone 3 days, his daughter stays 4 days a week, CM as case manager, COPD, Breathlessness, Angina, Short term memory loss, 10 medications. On caseload 22 months prior to referral

Baseline usual services:	**Services received for months 2 to 9 → frequency of contact**							
MONTH 1: F:INTERVIEW	**MONTH 2: T:INTERVIEW**	**MONTH 3: T:INTERVIEW**	**MONTH 4 T:INTERVIEW**	**MONTH 5 F:INTERVIEW**	**MONTH6 T:INTERVIEW**	**MONTH 7 T:INTERVIEW**	**MONTH 8 T:INTERVIEW**	**MONTH 9 F:INTERVIEW**
CMx4 **GP**prn **Podiatrist 3 mthly** **OPd yearly** **OPg** 6 monthly	**CMx1** (CM on hols) **Podiatristx1**	**CMx7** **GPx1**	**CMx4**	**CMx4** **OP g x1**	**CMx4** **GPx1** **Podiatrist x1**	**CMx4** **OP d x1**	**CMx4**	**CMx4**
Exacerbations and falls			⚡		⚡		⚡	
Change in Condition		**Earache**	**Chest infection**					
Treatment/ Referrals								
		CM - drops	**antibiotics steroids - CM**					
Euroqol scores: →90	**80**	**85**	**95**	**90**	**90**	**95**	**80**	**83**

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Patient 6 Community Matron as case manager

Patient profile: Female 82 years lives alone, community matron as case manager, heart failure, asthma, underactive thyroid, chronic pain, 9 medications. On caseload 1 month prior to referral

Baseline usual services:	Services received for months 2 to 9 → frequency of contact							
MONTH 1: F:INTERVIEW	MONTH 2: T:INTERVIEW	MONTH 3: T:INTERVIEW	MONTH 4 T:INTERVIEW	MONTH 5 F:INTERVIEW	MONTH6 T:INTERVIEW	MONTH 7 T:INTERVIEW	MONTH 8 T:INTERVIEW	MONTH 9 F:INTERVIEW
CM x2 GP prn Physio x2/wk PC 6dys/wk OP 3mthly OP rheumatology yrly OP orthopaedic 3mthly	CM x1 GP x1 by CM Phlebotomist x1 Physio x2 PC 6dys/wk OP urology x1 Cardiac exercise grp x4	CM x1 GP x1 by CM CNS x2 PC 6dys/wk Cardiac exercise grp x4	CM x2 Phlebotomist x1 PC 6dys/wk Cardiac exercise grp x4	CM x1 PC 4dys/wk OP rheumatology x1 Cardiac exercise grp x4	CM x1 GP x1 PC 4dys/wk OP orthopaedic x1 Cardiac exercise grp x4	NO INTERVIEW THIS MONTH	GP x1 whilst staying with daughter	CM x1 PC 4dys/wk Attended cardiac seminar Cardiac exercise grp x4
Exacerbations and falls								
Change in Condition		Low BP, anaemia					Ankle injury	
Treatment/ Referrals								
	GP urology referral & painkillers prescribed	Medication management by CNS		Rheumatologist prescribed anti-inflammatory				
Euroqol scores: → 50	75	60	60	60	60	N/A	N/A	80

Patient 7 Community Matron as case manager

Patient profile: Male, 72, COPD (O2 reliant) Mobility restricted. 6 Medications Lives in own home with wife who is his carer.

Baseline usual services:	Services received for months 2 to 9 → frequency of contact							
MONTH 1: F:INTERVIEW	MONTH 2: T:INTERVIEW	MONTH 3: T:INTERVIEW	MONTH 4 T:INTERVIEW	MONTH 5 F:INTERVIEW	MONTH6 T:INTERVIEW	MONTH 7 T:INTERVIEW	MONTH 8 T:INTERVIEW	MONTH 9 F:INTERVIEW
CM 2x week DN weekly (Spriometry and blood, GP prn OP COPD 6 monthly	CM 2xmonth CM☎5 DN weekly GP☎x1	CM 1x month CM☎3 DN weekly DN TLx1 OOH x2	CM 2x weekly CM☎4 DN daily OOH x2	CM weekly CM☎1 DN daily DN TLx1	CM 1x month CM☎3 DN daily DN TLx1	CM 1x month CM☎6 DN daily	CM 0 CM☎2 DN daily	CM 2 x month CM☎1 DN daily DN TLx1
			A&E x1 ✚			A&E x1		
Exacerbations and falls		⚡	⚡⚡	⚡		⚡F		
Change in Condition		COPD worse	Flu type virus/pneumonia			Fractured wrist		
Pulmonary rehanbilitation	X4	X2						
Treatment/ Referrals		O2 increased	Refer to A&E by OOH Antibiotics/Nebuliser			Antibiotics		
Euroqol scores: → 45	60	80	70	40	90	60	70	70

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Patient 10 Community Matron as case manager

Patient profile: Male, 91, CHD/Kidney failure(Dialysis 3xweek), Cognitive impairment, deafness.. 16 medications. Lives alone, paid cleaner/carer 3x week. Grandson visits regularly and oversees care. 2 months on caseload before study.

usual services:	**Services received for months 2 to 9 → frequency of contact**							
MONTH 1: **F:INTERVIEW**	**month 2:** **t:interview**	**month 3:** **t:interview**	**month 4** **t:interview**	**month 5** **f:interview**	**month6** **t:interview**	**month 7** **t:interview**	**month 8** **t:interview**	**month 9** **f:interview**
CM 1 x 2week **DN🏠 on days when no dialysis. General check, dressings, bloods.** **GP🏠 prn** **OP CHD x 6monthly** **OPR 1x3 month** **OP Eye**	**CM 1 x 2week** **CM**☎5 **DN🏠 4xweek** **GP**☎x1 **✚P (pacemaker)**	**CM 1 x 2week** **CM**☎3 **DN🏠 4xweek** **GP**☎x2	**CM 1 x 2week** **CM**☎4 **DN🏠 4xweek** **GP**☎x1 **OP TV**	**CM 1 x 2week** **CM**☎1 **DN🏠 4xweek**	**CM 🏠1x month** **CM**☎3 **DN🏠 4xweek** **GP**☎x2 **✚P (cataracts)**	**CM 🏠1x month** **CM**☎6 **DN🏠 4xweek** **OP Aduiology**	**CM 🏠0** **CM**☎2 **DN🏠 4xweek** **GP**☎x3	**CM 1 x month** **CM**☎1 **DN🏠 4xweek** **GP**☎x4
Hospital transport to dialysis	**10**	**18**	**15**	**18**	**11**	**15**	**18**	**10**
Change in Condition						**New hearing aid .**		
Referred to audiology clinic, and suggested referreal to eye clinic to GP	**CM referral to SS refused patient**							
Euroqol scores:	**70**	**80**	**80**	**80**	**70**	**80**	**70**	**75**

Patient 16Community Matron as case manager

Patient profile: Male, 70. COPD/CHD/Bilateral Uncers/Osteosporosis/Mobility. Lives in own home with wife who is his carer. Family close by, active social life. 3 months on caseload before study.

Baseline usual services:	Services received for months 2 to 9 → frequency of contact							
month 1: f:interview	month 2: t:interview	month 3: t:interview	month 4 t:interview	month 5 f:interview	month6 t:interview	month 7 t:interview	month 8 t:interview	month 9 f:interview
CM 2x month Check and review/advice and support DN 4 x week– dressings, BP., Lung function GP weekly OP♥ 3 monthly OPCOPD 6 monthly OP geron 1x year OP VS 6 monthly	CM 2x month DN 4 x week GP weekly OP♥ OPCOPD	CM 2x month DN 4 x week GP weekly OP OPTH	CM 2x month DN 4 x week GP weekly ✚	CM 2x month DN 4 x week GP weekly OP♥	CM 1x month DN 7x week GP weekly OP VS	CM 1x month DN 7 x week GP weekly OP geron ✚P	CM 2x month DN 4 x week GP weekly OP♥	CM 2 x month DN 3 x week GP weekly
Exacerbations and falls			⚡	⚡	⚡ ⚡			⚡
Change in Condition	Referred to opthalomlogist – failing sight	MD diagnosed	Chest pain	New ulcer	Infected iulcer	Ulcer eviscerated		New ulcer
Treatment/ Referrals			In hospital for observation		Antibiotics Honey dressings	Antibiotics		
Euroqol scores: 80	80	80	80	80	80	80	80	80

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Patient 24 District nurse as case manager

Patient profile: Female, 74, COPD/Tracheotomy/Scoliosis/Colostomy/Mobility and function. Lives alone in own retirement flat. Daughter lives close. Paid carer daily. 6 months on caseload before study.

Baseline usual services:	Services received for months 2 to 9 → frequency of contact							
MONTH 1: F:INTERVIEW	MONTH 2: T:INTERVIEW	MONTH 3: T:INTERVIEW	MONTH 4 T:INTERVIEW	MONTH 5 F:INTERVIEW	MONTH6 T:INTERVIEW	MONTH 7 T:INTERVIEW	MONTH 8 T:INTERVIEW	MONTI F:INTE W
DN 3x week and on call Check trache, assessments, colostomy bag, Bloods/BP/Spriometry/Other ingformal help. GP prn Bowel/COPD/Orthopaedic/Geriatric/COPD specialists all once every 3 months/ Paid Carer daily	DN 3xweek GP☎x3 OPCOPD OP A Paid Carer daily	DN 3x week GP☎x1 OPB Paid Carer daily	DN 5x week GP OP G Paid Carer daily	DN 7x week GP☎x1 OPCOPD OP A Paid Carer daily	DN 3x week GP☎x1 OPB Paid Carer daily	DN 2x week OOH x2 OP G Paid Carer daily	DN 2x week GP☎x2 OPCOPD OP A Paid Carer daily	DN 2 GP Cat Sca OPB Paid da
Daughter visits daily								
Exacerbations and falls								
Change in Condition		Colostomy sinus infected	Problems with colostomy Back pain	Problems with trache blocking	Pain in limbs and belly	Problems with colostomy General pain	Problems with colostomy Exacerbation of COPD	Termir cancer diagnc
Treatment/ Referrals		Antibiotics Pain killers		Pain killers	Pain killers			
Euroqol scores: 70	70	60	40	40	50	40	30	Not a

Patient 31 District nurse as case manager

Patient profile: Female, 88, Diabetes, cognitive impairment, falls. 3 medications Lives in own home with husband, who is her carer. Local family and friends. 3 months on caseload before study.

Baseline usual services:	Services received for months 2 to 9 → frequency of contact							
MONTH 1: F:INTERVIEW	MONTH 2: T:INTERVIEW	MONTH 3: T:INTERVIEW	MONTH 4 T:INTERVIEW	MONTH 5 F:INTERVIEW	MONTH6 T:INTERVIEW	MONTH 7 T:INTERVIEW	MONTH 8 T:INTERVIEW	MONTH 9 F:INTERVIEW
DN 1 x week (Bloods/advice and support/liason with other services) GPprn OP D 2 xyr OPGer 2x yr Physio and OT as needed	DN 1 x week month DN☎x2	DN 1 x week DN☎x3 GP OP D	DN 5 x week DN☎x8 ✚P (overnight for observation)	DN 1 x week DN☎x3 GP x 3	DN 1 x week DN☎x3 OPGer	DN 1 x week DN☎3	DN 1 x week DN☎x3 OOH x1 ✚P	DN 1 x week DN☎x3 OP D
Physio assessment	OT assessment		Phsyio x1	Phsyio x5	Phsyio x2			
Exacerbations and falls			F					
Change in Condition			Dislocated knee and twisted ankle					
Treatment/ Referrals	Referral to SS				SS			
Euroqol scores: 60	20	10	100	30	20	70	70	60

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Patient 29 District nurse as case manager

Patient profile: Male, 71, Diabetes/mobility/sight loss/Osteoarthritis. 8 Medications., DN is case manager, lives in owned house with wife who is carer – and he is her carer. 2 months on caseload before study

Baseline usual services:	Services received for months 2 to 9 → frequency of contact							
MONTH 1: F:INTERVIEW	MONTH 2: T:INTERVIEW	MONTH 3: T:INTERVIEW	MONTH 4 T:INTERVIEW	MONTH 5 F:INTERVIEW	MONTH6 T:INTERVIEW	MONTH 7 T:INTERVIEW	MONTH 8 T:INTERVIEW	MONTH 9 F:INTERVIEW
DN 2x week GP prn OP D 1x year OP OP1x 3 month	DN 2x week OPOP	DN 2x week GP☎x3	DN 2x week GP☎x1	DN 5x week GP x1 OPOP	DN 5x week GP x1 ✚A&E	DN 7x week GP x1	DN 2x week GP x1 OPOP	DN 2x week GP x1
		New GP						
Exacerbations and falls								
⌁	⌁ ⌁	⌁ ⌁ ⌁ ⌁	⌁	⌁	F			
Change in Condition								
		Antibiotics Insulin dose increased	Antibiotics		Pain killers Antibiotics			
Euroqol scores: 65	50	60	70	70	60	80	80	85

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Patient 36 Clinical Nurse Specialist as case manager

Patient profile: Male 67 years lives with his wife, nurse specialist as case manager; Aortic valve replacement, nephrectomy for Ca kidney, on 3 medications. On the cardiac nurse specialist caseload for 3 months.

Baseline usual services:	**Services received for months 2 to 9 → frequency of contact**							
MONTH 1: F:INTERVIEW	**MONTH 2: T:INTERVIEW**	**MONTH 3: T:INTERVIEW**	**MONTH 4 T:INTERVIEW**	**MONTH 5 F:INTERVIEW**	**MONTH6 T:INTERVIEW**	**MONTH 7 T:INTERVIEW**	**MONTH 8 T:INTERVIEW**	**MONTH 9 F:INTERVIEW**
CNS x1 **GP** prn **OP** yearly **OP** urology 6mthly	**CNS** x1 **GP** x1 **Physio** x2	**CNS** x1 **GP** x1 **Physio** x2 **OP** x1	**Physio** x2 **OP** urology	**CNS** x1	**CNS** x1 **GP** x1	**NO INTERVIEW THIS MONTH**	**CNS** x1	**CNS** x1
Exacerbations and falls								
Change in Condition		**Fluid on his lung**						
Treatment/ Referrals								
	Physio for shoulder pain	**Diuretics 3 day course**		**Statin for high cholesterol**				
Euroqol scores: 80→	**80**	**75**	**80**	**100**	**80**		**80**	**90**

Patient 33Community Nurse Specialist as case manager

Patient profile: Male 67 years lives with his wife, nurse specialist as case manager; Aortic valve replacement, nephrectomy for Ca kidney, on 3 medications. On the cardiac nurse specialist caseload for 3 months.

Baseline usual services:	**Services received for months 2 to 9 → frequency of contact**							
MONTH 1: F:INTERVIEW	**MONTH 2: T:INTERVIEW**	**MONTH 3: T:INTERVIEW**	**MONTH 4 T:INTERVIEW**	**MONTH 5 F:INTERVIEW**	**MONTH6 T:INTERVIEW**	**MONTH 7 T:INTERVIEW**	**MONTH 8 T:INTERVIEW**	**MONTH 9 F:INTERVIEW**
CNS x1 **GP** prn **OP** ♥ yearly **OP** urology 6mthly	**CNS** x1 **GP** x1 **Physio** x2	**CNS** x1 **GP** x1 **Physio** x2 **OP** ♥ x1	**Physio** x2 **OP** urology	**CNS** x1	**CNS** x1 **GP** x1	**NO INTERVIEW THIS MONTH**	**CNS** x1	**CNS** x1
Exacerbations and falls								
Change in Condition								
		Fluid on his lung						
Treatment/ Referrals								
	Physio for shoulder pain	**Diuretics 3 day course**		**Statin for high cholesterol**				
Euroqol scores: 80→	**80**	**75**	**80**	**100**	**80**		**80**	**90**

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Patient 47 Nurse Practitioner as case manager

Patient profile: Female 77, lives with husband who is her carer, nurse practitioner is her care manager osteoarthritis, hypertension, macular degeneration, registered blind, 5 medications. On caseload 2 months prior to referral

Baseline usual services:	**Services received for months 2 to 9 → frequency of contact**							
MONTH 1: F:INTERVIEW	**MONTH 2: T:INTERVIEW**	**MONTH 3: T:INTERVIEW**	**MONTH 4 T:INTERVIEW**	**MONTH 5 F:INTERVIEW**	**MONTH6 T:INTERVIEW**	**MONTH 7 T:INTERVIEW**	**MONTH 8 T:INTERVIEW**	**MONTH 9 F:INTERVIEW**
NP x1 **GP prn** **OP** Ophthalmic **6mthly** **RNIB prn**	**DN x1** **Sensory unit home visit x1** **OP** Ophthalmic **x1**	**DN ☎ x1** **Sensory unit home visit x1**	**Sensory unit ☎ x1**	**DN x2** **Sensory unit ☎ x2** **RNIB visit x1**	**No interview**	**DN x1** **counsellor x1** **RNIB visit x1**	**No interview**	**GP x1** **DN x1**
Exacerbations and falls								
Change in Condition								
Bronchitis **High BP**								
Treatment/ Referrals								
Antibiotics – NP **DN referral to monitor BP – NP** **Sensory unit referral**				**Referral to counsellor – Sensory unit**				**Discharged from sensory unit**
Euroqol scores: → 10	**50**	**65**	**50**	**40**	**N/A**	**50**	**N/A**	**60**

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KEY TO TIMELINES

Explanation	Symbol	Explanation	Symbol
Face to Face interview	F:INTERVIEW	Hospital outpatient appointment - neurologist	OP N
Telephone interview	T:INTERVIEW	Hospital outpatient appointment - orthopaedic	OP Orth
A and E visit	A&E	Hospital outpatient appointment - renal	OP R
Community Centre	cc	Hospital outpatient appointment - respiratory	OP
Community nurse specialist	CNS	Leg ulcer clinic	LU
Community Matron phone call	CM☎	Meals on Wheels	Meals
Community Matron visit	CM🏠	Medication delivered	Pharmacist
District nurse phone call	DN☎	Nurse specialist phone call	CNS ☎
District nurse team leader	DN🏠TL	Nurse specialist visit	CNS🏠
District nurse visit	DN🏠	Occupational therapist	OT
Exacerbation	⚡	Out of hours GP home visit	OOH 🏠
Fall	F	Paid carer	☺

Gerontologist	OP Geron	Patient helpline and service access	Careline
GP home visit	GP	Physiotherapist	**Physio**
GP phone call	GP☎	Practice nurse consultation	PN
GP surgery consultation	GP	Private Carer	**PC**
Heart specialist	OP CHD	Psychologist	**OP PSYCH**
Hospital inpatient – planned	**+P**	Social services	**SS**
Hospital inpatient	+	Telephone helpline	**helpline**
Hospice inpatient	+	Telephone shopping	**Shop**☎
Hospital outpatient appointment - arthritis	**OP A**	Voluntary organisation	**VO**
Hospital outpatient appointment - bowel	**OP B**	Well ulcer clinic	**WU**
Hospital outpatient appointment - cardiac	**OP**♥		
Hospital outpatient appointment - COPD	COPD/Ý		
Hospital outpatient appointment - geriatric	**OP G**		
Hospital outpatient appointment – psychiatrist	OPPsych		

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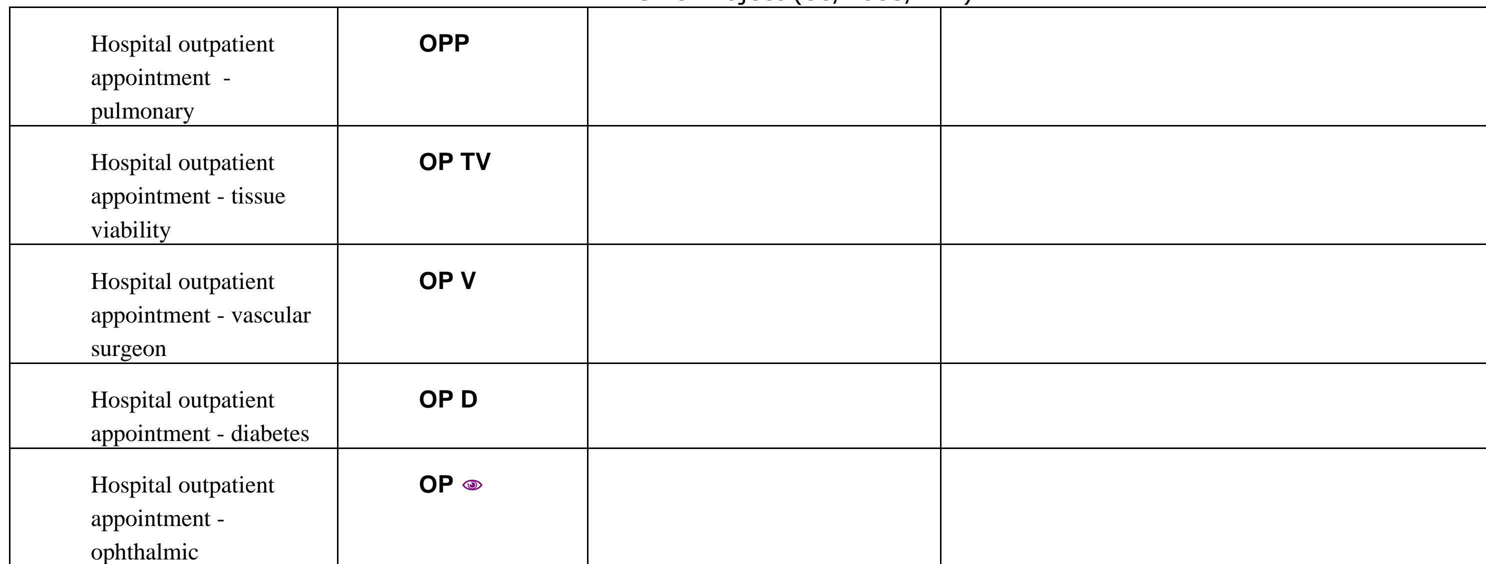

Hospital outpatient appointment - pulmonary	**OPP**		
Hospital outpatient appointment - tissue viability	**OP TV**		
Hospital outpatient appointment - vascular surgeon	**OP V**		
Hospital outpatient appointment - diabetes	**OP D**		
Hospital outpatient appointment - ophthalmic	**OP** 👁		

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Appendix 7 Unit Costs used in the Economic Analysis

Service use	Service	Estimated cost (for home visit [IH] and out of home consultations [OH])	Source
Nurse case manager usage (based on mean number of hours per month)	Community matron and Nurse Practitioner	Home visit per hour £90 + £1.40 travel per visit (pro rata based on salary scale and district nurse home visit rate) Clinic consultation per hour £69	Curtis 2008, p107
	Community Nurse Specialist	Home visit per hour £81 + £1.40 travel per visit Clinic consultation per hour £58 (pro rata based on district nurse clinic consultation rate)	Curtis 2008, p104
	District Nurse	Home visit per hour £73 + £1.40 travel per visit Clinic consultation per hour £52	Curtis 2008, p101
Nurse consultations (based on mean number of visits per month)	Community Nurse Specialist	Per home visit £27 + £1.40 travel per visit (20 minutes) Per clinic consultation £14.50 (15 minutes)	Curtis 2008, p104
	District Nurse	Per home visit £24 + £1.40 travel per visit (20 minutes) Per clinic consultation £13 (15 minutes)	Curtis 2008, p101
	Practice Nurse	Per surgery consultation £11 (15 minutes)	Curtis 2008, p106
GP consultations (based on mean number of consultations per month)		Per home visit £58 (23.4 minutes, including travel time and out of hours consultations) Per surgery consultation £36 (11.7 minutes) Per telephone consultation £22 (7.1 minutes) NB: includes direct care staff and qualification costs	Curtis 2008, p109
Other including Allied Health Professionals (AHP; based on mean number of consultations per month)	Counsellor	Per surgery consultation £64 (96.6 minutes)	Curtis 2008, p132
	Dentist	Per home visit £80 NB: national average unit cost	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTOCS
	Occupational therapist	Per home visit £46 + £2.60 travel per visit (60 minutes)	Curtis 2008, p94
	Optician	Per home visit £38 NB: mean of national average unit cost for face to face contact	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet

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Service use	Service	Estimated cost (for home visit [IH] and out of home consultations [OH])	Source
			tab name – TPCTCSHVO
	Pharmacist delivery	Per home visit £36	Curtis 2008, p98
	Phlebotomist	Per home visit £20 (60 minutes) NB: assuming similar costs for social work assistant, 60 minutes time spent and hourly rate of £20	Curtis 2008, p115
	Physiotherapist	Per home visit £47 + £2.60 travel per visit (60 minutes) Per surgery consultation £34 (30 minutes)	Curtis 2008, p93
	Podiatrist/Chiropodist	Per home visit £20 + £1.40 travel per visit Per surgery consultation £11	Curtis 2008, p96
	Pulmonary Rehabilitation Clinic and Sensory Perception Unit	Per outpatients attendance £54 NB: national average unit cost, based on community physiotherapy group based intervention	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTCSCT
Pathology tests NB: national average unit cost used	Haematology	Per blood test £3	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTDAPS
	Urine test	Per urine test £4 NB: category used “Other”	
Hospital outpatients clinics (based on mean number of consultations per month) NB: unless otherwise stated, costs used means of first and follow up attendance costs National average unit cost used *consultant led,	Anti-coagulation (nurse led)	Per attendance %£16, %%£20 (Mean £18) Per attendance &£19, &&£19 (Mean £19)	
	Audiology	Per attendance *£103, **£279 (Mean £191)	
	Cardiology	Per attendance *£105, **£160 (Mean £132.50) Per attendance ^£125, ^^£160 (Mean £142.50)	
	Diabetic Medicine	Per attendance *£106, **£189 (Mean £147.50) Per attendance ^£158, ^^£347 (Mean £252.50)	
	Echocardiogram (non-consultant led)	Per attendance £70 NB: national average unit cost	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTDADS
	Geriatric Medicine	Per attendance *£137, **£208 (Mean £222.50) Per attendance ^£102, ^^£146 (Mean £124)	

Service use	Service	Estimated cost (for home visit [IH] and out of home consultations [OH])	Source
face to face, non-admitted attendance follow up, **first ^consultant led, multidisciplinary, face to face, non-admitted attendance follow up, ^^first %non-consultant led, face to face, non-admitted attendance follow up, %%first non-consultant led, multidisciplinary, &face to face, non-admitted attendance follow up, &&first National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – *TPCTCLFUSFF, **TPCTCLFASFF ^TPCTCLFUMFF, ^^TPCTCLFAMFF, %TPCTNLFUSFF, %%TPCTNLFASFF, &TPCTNLFUMFF, &&TPCTNLFAMFF	Neurology	Per attendance *£128, **£197 (Mean £162.50) Per attendance ^£165, ^^£318 (Mean £241.50)	
	Ophthalmology	Per attendance *£65, **£106 (Mean £85.50) Per attendance ^£83, ^^£150 (Mean £116.50)	
	Orthopaedics (trauma)	Per attendance *£78 **£121 (Mean £99.50) Per attendance ^£83, ^^£147 (Mean £115)	
	Orthopaedics (non-trauma)	Per attendance *£81 **£122 (Mean £101.50) Per attendance ^£84, ^^£157 (Mean £120.50)	
	Orthopaedics (trauma and non-trauma)	*Per attendance £85.50, £99.50 (Mean £92.50) ^Per attendance £116.50, £120.50 (Mean £118.50) NB: calculated based on means of above 2 categories of orthopaedics (trauma) and (non-trauma)	
	Psychiatrist	NB: this category not available, used Geriatric Medicine estimates	
	Respiratory Medicine	Per attendance *£118 **£186 (Mean £152) Per attendance ^£92, ^^£178 (Mean £135)	
	Rheumatology	Per attendance *£115, **£203 (Mean £159) Per attendance ^£86, ^^£153 (Mean £119.50)	
	Tissue viability (nurse-led)	Per attendance %£72 %%£112 (Mean £92) NB: category used "Vascular surgery"	
	Urology	Per attendance *£82, **£127 (Mean £104.50) Per attendance ^£139, ^^£97 (Mean £118)	
	Vascular surgery	Per attendance *£89, **£140 (Mean £114.50) Per attendance ^£77, ^^£172 (Mean £124.50)	
	Visual aids unit (non-consultant led)	Per attendance %£48 %%£74 (Mean £61) Per attendance &£48, &&£95 (Mean £71.50) NB: category used "Ophthamology"	
A&E visits (based on mean number of visits per month)	A&E	Per visit £111	Curtis 2008, p81
Planned hospital stays (based on mean number of planned hospital days per month)	Cataract	Per bed day £2009/1.37 = £1466.42	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTEI
	Complications of procedure	Per bed day without CC £1198/2.22 = £539.64 Per bed day with intermediate CC £2161/4.82 = £448.34 Per bed day with major CC £3008/6.98 =	

Service use	Service	Estimated cost (for home visit [IH] and out of home consultations [OH])	Source
NB: unless otherwise stated, Per bed day calculated from national average unit cost and average length of stay days		£430.95 NB: mean of all 3 categories used £472.98	
	Head injury	Per bed day without CC £1911/1.56 = £1225 Per bed day with CC £416/1.08 = £385.19 Per bed day with major CC £1902/5.33 = £356.85 NB: mean of all 3 categories used £655.68	
	Lobectomy	Per bed day without CC £950/1.62 = £586.42 Per bed day with CC £1047/2.11 = £496.21 NB: mean of both categories used £541.32; (this category or general surgery not available, used "other procedures and healthcare problems")	
	Observations	Per bed day £837/1.47 = £569.39	
	Pacemaker fitting	Per bed day £3545/2.87 = £1235.19	
	Vascular surgery	NB: this category not available, as for lobectomy above	
Unplanned hospital stays (based on mean number of unplanned hospital days per month) NB: unless otherwise stated, National average unit cost used National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTNEI_L	Chest pain	Per bed day £686/1.86 = £368.82	
	COPD with *intubation, ^with NIV without intubation, $without NIV without intubation	Per bed day without CC *£1521/9.25 = £164.43, ^£1522/5.95 = £255.80, $£1288/4.69 = £274.63 (Mean £231.62) Per bed day with CC *£1822/6.02 = £302.66, ^£1855/7.33 = £253.07, $£1537/5.76 = £266.84 (Mean £274.19) Per bed day with major CC *£2764/11.93 = £231.68, ^£2835/11.26 = £251.78, $£2502/9.99 = £250.45 (Mean £244.64) NB: mean of all 3 categories used £250.15	
	Coronary Heart Disease (CHD) exacerbation	Per bed day without CC £1399/4.49 = £311.58 Per bed day with CC £1779/5.36 = £331.90 NB: mean of both categories used £321.74; (this category not available, used "other procedures and healthcare problems")	
	Eyelid cyst removal	NB: this category or general surgery not available, as for CHD exacerbation above	
	Falls	Per bed day without CC £1156/4.27 = £270.73 Per bed day with intermediate CC £1739/6.73 = £258.40 Per bed day with major CC £2356/9.42 = £250.10 NB: mean of all 3 categories used £259.74	
	Heart failure	Per bed day cardiac arrest £1683/5.19 = £324.28	

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Service use	Service	Estimated cost (for home visit [IH] and out of home consultations [OH])	Source
		Per bed day cardiac conditions without CC £1932/3.11 = £621.22 Per bed day cardiac conditions with CC £4263/5.25 = £812 NB: mean of all 3 categories used £585.83	
	Investigations	Per bed day £1260/2.46 = £512.20 Per bed day full investigations £1690/3.43 = £492.71 NB: mean of both categories used £502.46	
	Observations	Per bed day £1175/2.24 = £524.55	
	*(Lobar, atypical or viral) or ^broncho-pneumonia	Short stay: Per bed day without CC *£331/1 = £331, ^£324/1 = £324 (Mean £327.50) Long stay: Per bed day without CC *£1105/3.96 = £279.04, ^£1293/5.2 = £248.65 (Mean £263.85) Mean £295.68 Short stay: Per bed day with CC *£338/1 = £338, ^£331/1 = £331 (Mean £334.50) Long stay: Per bed day with CC *£1635/6.21 = £263.29, ^£1766/6.92 = £255.20 (Mean £259.25) Mean £296.88 Short stay: Per bed day with major CC *£355/1 = £355, ^£345/1 = £345 (Mean £350) Long stay: Per bed day with major CC *£2826/11.48 = £246.17, ^£2913/12.09 = £240.94 (Mean £243.55) Mean £296.78 NB: mean of all 3 categories used £296.45	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTNEI_S (short stay), TPCTNEI_L (long stay)
	Transient ischaemic attack	Per bed day £1046/3.85 = £271.69	
Hospice stays (based on mean number of hospice days per month)	*Respite care or ^Convalescent or other relief care	Per bed day *£532/1 = £532, ^£506/1 = £506	National Schedule of Reference Costs 2007-08 for NHS Trusts and PCTs Combined extended: Sheet tab name – TPCTNEI_S
Careline	Careline subscription (Gold service)	Monthly subscription (irrespective of usage) £17.33	NB: different costs exist for this service depending on PCTs, ranging from £3-£5 per week; therefore

Service use	Service	Estimated cost (for home visit [IH] and out of home consultations [OH])	Source
			mean was used.
Meals on wheels	Meals on wheels subscription	Monthly subscription (irrespective of usage) £38	Curtis 2008, p38
Social Care Assistance	Social care assistant	Per hour of client-related work £24 Monthly wage costs £31043/12 = £2586.92 (including overheads; used for live-in assistants)	Curtis 2008, p115

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